

# **POLICY AND PROCEDURE MANUAL**

FOR REPORTING FACILITIES

March 2003

Effective For Cases Diagnosed January 1, 2003 and Later

Indiana State Cancer Registry Indiana State Department of Health 2 North Meridian Street, Section 7-D Indianapolis, IN 46204-3010

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The Indiana State Cancer Registry Policy and Procedure Manual for Reporting Facilities was written by Jacqueline S. Harber, RHIA with Martha Graves, RHIA, CTR of the Indiana State Department of Health and is in the public domain. The manual itself may be copied all, or in part.

The SEER (Surveillance, Epidemiology, and End Results) Program Summary Staging Guide, April 1977, is Publication Number 86-2313 of the U.S. Department of Health and Human Services, Public Health Service.

Re-printed 1998, Indiana State Department of Health.

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## **ACKNOWLEDGMENTS**

The State Cancer Registry gratefully acknowledges the dedication, time, and effort the following organizations and individuals have made in order to make the reporting system and this manual a reality.

Rocky Mountain Cancer Data Systems Indiana Cancer Registrars Association Commission on Cancer, American College of Surgeons Anita Butz, CTR, Helping Hands, Indianapolis, Indiana

## INTRODUCTION

## A. BACKGROUND

In 1985, the General Assembly of the State of Indiana passed Public Law 174-1985 establishing a cancer registry "for the purpose of recording all cases of malignant disease that occur in Indiana residents and compiling necessary and appropriate information concerning those cases...in order to conduct epidemiologic surveys of cancer and to apply appropriate preventive and control measures."

An advisory committee was established to assist the State Department of Health in creating such a registry. The committee developed the standards for establishing and maintaining the State Cancer Registry. They also helped develop a Policy and Procedure Manual and implemented training throughout the state. Hospitals, physicians, dentists, and medical laboratories began reporting January 1, 1987.

A 1988 amendment to the law allows the State Cancer Registry to release confidential information to another state's cancer registry if that state has entered into a reciprocal agreement with the State Department of Health. The reciprocal agreement must state that information that identifies a patient will not be released to any other entity without the written consent of the patient.<sup>2</sup>

In 1991, IC 16-4-9-3 was amended to allow the state to enter into reciprocal agreements with other states in order to exchange data between cancer registries.

In a 1993 amendment, several laws were recodified. No substantial changes were made other than some minor wording changes, such as changing "State *Board* of Health" to "State *Department* of Health." The current law is IC 16-38-2.

This manual has been revised from the edition released in 1995 to reflect current laws and standards.

#### B. PURPOSE

The intent of this manual is to serve as a reference for hospitals reporting cases of malignant disease to the State Cancer Registry. The procedures set out in the manual have been developed in accordance with IC-38-2 and 410 IAC 21-1 (Appendix A).

## C. DEFINITIONS

The terms *must, shall,* and *is required* are used throughout the manual to indicate what is mandatory and the only acceptable method under the law and rule. *Should* is used to reflect commonly accepted practices, yet allows effective alternatives to be used. *May* is used to indicate an alternative that is acceptable, but not necessarily preferred.

## D. REFERENCE MATERIALS

This Policy and Procedure Manual serves as a reference which is offered free of change to reporting entities. All required references except the *International Classification of Diseases for Oncology, Third Edition,* are contained in this Policy and Procedure Manual. For a complete list of required references and other resources, see Chapter 1.

<sup>&</sup>lt;sup>1</sup> IC 16-4-9 (IC 16-38-2 since 1993)

<sup>&</sup>lt;sup>2</sup> IC 16-4-9-6 (IC-38-2-6 since 1993)

## **E. CONSULTATION**

Personnel of the State Cancer Registry are available by telephone and, in special circumstances, on site to provide consultation on all aspects of reporting. These include abstracting, organization and management, cancer registry software education, and updates on cancer data management at the both the state and national level. The Indiana Cancer Registrars Association has graciously offered to serve as a source for consultation, utilizing the expertise of experienced cancer registrars across the state.

## F. OUTPUT

The rule for implementing statewide reporting mandates that the state provide each reporting facility a comprehensive annual report which outlines the trends of malignant disease in Indiana. Hospitals, physicians, dentists, medical laboratories, and other persons may request and be provided with individualized special reports as state resources permit.

#### **G. QUALITY CONTROL**

The State Cancer Registry monitors data quality through a variety of activities that are described in Chapter 7. The activities include careful monitoring of the number of cases submitted, visual review of paper reports for completeness and accuracy, and extensive edits of machine-readable data. Chapter 7 provides policies for clarification and modification of data. Continuing education and policy and procedure updates will focus on issues identified through quality control activities.

In summary, the State Cancer Registry serves as the state's repository of cancer data and an important resource offering a wide spectrum of services to the hospitals, physicians, dentists, and medical laboratories reporting to the State. As a tax supported service to health care professionals and the public, feedback regarding improvements in State Cancer Registry policies and services is welcomed.

## **CHAPTER 1: REFERENCES**

This Policy and Procedure Manual serves as a reference that is offered free of charge to reporting entities. All required references except the *International Classification of Diseases for Oncology, Third Edition*, are contained in this Policy and Procedure Manual.

## A. REQUIRED REFERENCES

- 1. Indiana State Cancer Registry Policy and Procedure Manual, Month 2001.
- SEER Summary Staging Manual 2000: Codes and Coding Instructions, National Cancer Institute, NIH Pub. No. 01-4969, Bethesda, MD, 2001. Effective for cases diagnosed January 1, 2001 forward. Order Through the State Cancer Registry or see page 3 to order directly.
  - <u>SEER Summary Staging Guide</u> Cancer Surveillance, Epidemiology, and End Results Reporting Program, April 1977 (Reprinted July 1986). Effective for cases diagnosed through 2000.
- International Classification of Diseases for Oncology, Third Edition (ICD-O-3). World health Organization, Geneva, Switzerland, 2000. Effective for cases diagnosed January 1, 2001 forward.

International Classification of Diseases for Oncology, Second Edition (*ICD-O-2*). World health Organization, Geneva, Switzerland, 1990. Order for \$24.00 plus \$5.00 shipping and handling from:

College of American Pathologists Attn: Linda Scott 325 Waukegan Road North field, IL 60093-2750 1-847-832-7000

The first two required references above are available free of charge to reporting entities by call or writing the State Cancer Registry. Hospitals are responsible for obtaining their own copy of the required *ICD-O-3*.

## **B. ADDITIONAL RESOURCES**

The following list identifies resources that may provide helpful information for use in the collection and abstraction of cancer data. References with an asterisk (\*) may be especially useful to hospital registries.

- \*ACS Textbook of Clinical Oncology, American Cancer Society, 1995. Order by calling 1-800-ACS-2345. (\$7.00)
- 2. \*AJCC Cancer Staging Manual, Fifth Edition, American Joint Committee on Cancer (AJCC), 1997. Order for \$49.00 from:

Lippincott – Raven FAX: (301) 824-7390

P.O. Box 1600 E-mail: Irorders@phl.lrpub.com

Hagerstown, MD 21741-1600 http://www.lrpub.com

Hagerstown, MD 21741-16 Phone: 1-800-777-2295

- 3. <u>AJCC Comparison Guide</u> <u>Fourth to Fifth Editions</u>, American Joint Committee on Cancer, Executive Office, 633 St. Clair, Chicago, IL 60611, (312) 202-5085, September 1997.
- 4. The Anatomy Coloring Book, W. Kapit and L. Elson, Harper and Row, 1975.

References Chapter 1

- 5. Annual Cancer Statistics Review, National Cancer Institute, current year.
- 6. <u>Cancer Facts and figures</u> <u>2001</u>, American Cancer Society. (Free) This provides an annual summary of national estimates of cancer incidence and mortality by state and site, as well as other useful cancer related information and specific issues of current importance.
- 7. \*Cancer Program Manual, American College of Surgeons, Commission on Cancer, P.O. Box 92425, Chicago, IL 60675-2425, 1996. Make checks for \$10.00 payable to American College of Surgeons.
- 8. <u>Cancer Registry Follow-Up Manual</u>, Cynthia M. Creech, Regional Activities Program, USC Comprehensive Cancer Center, May 1982. Available free of charge from the American College of Surgeons.
- 9. <u>Cancer Registry Management</u>: <u>Principles and Practice</u>, Hutchison, Roffers, and Fritz (eds.), NCRA, Kendall/Hunt Publishing Co., 1997. (\$79.95 NCRA members, \$99.95 non-members plus shipping and handling)
- 10. "Case Finding and Case Definition," Shirley Foret, CTR, National Tumor Registrars Association Abstract, March 1991.
- 11. <u>Central Cancer Registries</u>: <u>Design, Management and Use, H. R. Menck/C. R. Smart, New York:</u> Gordon & Breach, 1994. (\$20.00)
- 12. \*Classification and Staging of Cancer Correlation Charts for Oncology, Fourth Edition, April Fritz and Steven Roffers, P.O. Box 7851, Gaithersburg, MD 20898-7851, 1995. (\$14.00)
- 13. <u>Fundamental Tumor Registry Operations (FTRO) Program</u>, American College of Surgeons, 1992. Thirteen learning modules are used to teach fundamentals of cancer registry operations. Order from Harriet Jenkins, Cancer Department, (312) 664-4050 for \$850.00. Order revisions every eighteen months for \$100.00.
- 14. <u>Guidelines for Preparing a Hospital Cancer Program Annual Report</u>, American Cancer Society, California Division, Inc., 1982. (Distributed by the American College of Surgeons, Commission on Cancer)
- 15. "Indiana University School of Medicine/Ruth Lilly Library Oncology Page," http://www.medlib.iupui.edu/hw/onco/home.html
- International Classification of Diseases, Clinical Modification, Ninth Revision, Fourth Edition, (ICD-9-CM), Health Care Financing Administration, Public Health Service, U.S. Department of Health and Human Services, 1991.
- 17. National Program of Cancer Registries Act, Public Law 102-515, October 24, 1992.
- 18. "NCI PDQ TX Page for Health Professionals," Physician Data Query, National Cancer Institute, http://www.cancernet.nci, nih.gov/clinpdq/soa.html
- 19. <u>Professional Review for Tumor Registrars</u>, G. Clutter, et. al. (eds.), Florida Tumor Registrars Association, 1990.
- Quality Control for Cancer Registries, U.S. Department of Health and Human Services, 1987.
   Order from American College of Surgeons, Commission on Cancer, 633 St. Clair, Chicago, IL 60611, (312) 202-5085.

Chapter 1 References

21. \*Registry Operations and Data Standards (ROADS), Revised Edition, American College of Surgeons, Commission on Cancer, P.O. Box 92425, Chicago, IL 60675-2425, January 1996. Make checks payable to American College of Surgeons. The charge for printed copy is \$20.00 and for diskette, \$25.00.

- 22. Registry Staffing Manual, National Tumor Registrars Association, 1989. (Distributed by the American College of Surgeons, Commission on Cancer)
- 23. Robbins Pathological Basis of Disease, Fifth Edition, Ramzi S. Cotran, Vinay Kumar, Stanley L. Robbins, W. B. Saunders Co., October 1994, \$75.00. ISBN: 0721650325.
- 24. SEER Extent of Disease 1988, Codes and Coding Instructions, Second Edition, National Cancer Institute, National Institutes of Health, June 1992.
- 25. The SEER Program Code Manual, Revised Edition, National Cancer Institute, National Institutes of Health, June 1992.
- 26. SEER Program: Comparative Staging Guide for Cancer, Major Cancer Sites, Version 1.1, National Cancer Institute, National Institutes of Health, June 1993. (To be revised January 1998)
- 27. \*SEER Program: Self-Instructional Manuals for Tumor Registrars; Surveillance, Epidemiology, and End Results (SEER) Program Informational Guidebook Training Aids. This series of books provides a mechanism for tumor registrars to learn the procedures for abstracting from medical records of cancer patients and for carrying out functions in the institution-based tumor registry. The set consists of:

Book One Objectives and Functions of a Tumor Registry, Second Edition, 1980. Book Two Cancer Characteristics and Selection of Cases, Third Edition, 1992.

Tumor Registrar Vocabulary: The Composition of Medical Terms, Second Book Three

Edition, 1993.

Book Four Human Anatomy as Related to Tumor Formation, Second Edition, 1993.

Book Five Abstracting a Medical Record: Patient Identification, History, and Examinations,

Second Edition, 1993.

Book Six Classification for Extent of Disease, 1977.

Book Seven -Statistics and Epidemiology for Tumor Registrars, scheduled for publication in

- Antineoplastic Drugs, Third Edition, 1993. Book Eight

This set of books or any of the other SEER reference manuals may be obtained free of charge by calling or writing:

SEER Program/Cancer Statistics Branch National Cancer Institute Executive Plaza North, Room 343J 6130 Executive Boulevard, MSC 7352 Bethesda, MD 20892-7352 (301) 496-8510

1-800-4-CANCER (1-800-422-6237)

Fax: (301) 496-9949

 Standards for Cancer Registries, North American Association of Central Cancer Registries (NAACCR), March 14, 1997.

Volume I, Data Exchange Standards and Record Description, Version 3.0. Intended for programmers, this provides the record layout and specifications for the standard for data exchange.

References Chapter 1

Volume II, *Data Standards and Data Dictionary*. Intended for hospital and central cancer registries, programmers, and analysts, this provides detailed specifications and codes for each data item in the data exchange record layout.

Volume III, Standards for Completeness, Quality, Analysis, and Management of Data. Intended for central registries, this provides detailed standards for many aspects of the operation of a population-based cancer registry.

For information on ordering this set of books, contact:

Standards and Technical Assistance NAACCR Cancer Surveillance and Control Program 601 North 7<sup>th</sup> St. / MS 592 P.O. Box 942732 Sacramento, CA 94234-7320 Phone: (916) 567-1400

Fax: (916) 327-4657

 TNM Atlas, Third edition, B. Spiessl, et. al. (eds.), International Union Against Cancer, Springer-Verlag, reprinted 1993. Order for \$29.00 from:

Springer-Verlag New York, Inc. 175 Fifth Avenue New York, NY 10010 (800) 777-4643

- 30. Tumor Registry Desk Reference, April Fritz, (ed.), National Tumor Registrars Association, 1989.
- 31. <u>Tumor Registry Management</u>, Third edition, S. Watkins, Tumor Registrars Association of California, 1986.
- 32. Workbook for Staging of Cancer, An Instructional Manual for TNM Staging, Fritz, Hultstrom, McKee. Mail check or money order payable to NCRA for \$38.00 (\$23.00 for NCRA members) including shipping and handling to:

NCRA National Headquarters P.O. Box 15945-295 Lenexa, KS 66285-5945 (913) 438-NCRA (-6272) Fax: (913) 541-0156

E-mail: amp-info@applmeapro.com

- 33. Writing for Registrars: A Manual of Style for Annual Reports and Other Cancer Registry Technical Writing, April Fritz, ELM Publications, 1987.
- 34. Publications on follow-up, patient care evaluations, annual reports, and a variety of similar publications are also available by calling or writing:

Office of Public Information American College of Surgeons 633 St. Clair Chicago, IL 60611 (312) 202-5085 Chapter 1 References

35. Anatomy, physiology, pathology, and other similar textbooks are invaluable for coding and abstracting of cancer data. Medical dictionaries, such as Dorland's, Stedman's Blakinston's, Melloni's, or Taber's will also be needed.

36. For information regarding the National Cancer Registrars Association, Inc., write to:

NCRA National Headquarters P.O. Box 15945-295 Lenexa, KS 66285-5945 (913) 438-NCRA (-6272)

Fax: (913) 541-0156

E-mail: amp-info@applmeapro.com

To obtain the additional resources, call or write the publisher directly or call the State Cancer Registry for more information.

<u>References</u> Chapter 1

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## **CHAPTER 2: CASEFINDING & SETTING UP A REGISTRY**

#### A. OVERVIEW

The accuracy of a statewide database is dependent on the timeliness and completeness of casefinding (the identification of reportable cancer cases) at the hospital level. A variety of casefinding methods must be used since no single method can encompass all the possible medical resources used by cancer patients.

## **B. REPORTABLE LIST**

A reportable list identifies diagnoses that will be included in the registry and those that are to be excluded. The hospital's administration, cancer committee, and physicians; American college of Surgeons' Cancer Program Manual; and the State Policy and Procedure Manual should be consulted when developing the reportable list. Appendix B contains the State reportable list. All diagnoses on the list must be reported to the State Registry. The hospital cancer committee may decide to collect additional diagnoses not on the list, called "Reportable-by-Agreement" cases (e.g., benign brain tumors). These cases do not need to be reported to the State Registry.

## C. METHODS OF CASEFINDING

#### Definition

Casefinding is a systematic method of identifying all reportable cancer cases. For a hospital, the cases include all patients diagnosed or treated in a hospital, both inpatient and outpatient, during the first course of therapy. Cases identified at autopsy must also be reported.

## Responsibility

To assure consistency and completeness, casefinding should be the responsibility of one hospital department that has access to patients' medical records and the appropriate hospital reports and listings. For this reason, the function is most commonly performed in the medical record department. However, it may be performed elsewhere, such as pathology, radiation therapy, oncology, or nursing department, provided there is ready access to the necessary records and a central place for record keeping. The person responsible for casefinding should have a knowledge of medical terminology, especially in the field of cancer diagnosis and treatment. Interdepartmental communication and cooperation are essential for complete casefinding.

## Sources of Casefinding

The following are potential sources of cancer patient identification. Other sources, not listed here, may be appropriate, depending on the administrative structure of the hospital. To ensure that all potential sources of case identification are addressed, facilities should use the health information data systems and/or billing systems to print lists of cancer-related diagnostic codes. Casefinding should not be limited to a review of pathology reports. As potential cases are identified, the patient's name and medical record number should be recorded for retrieval of the entire medical record.

## 1. Pathology and Cytology Departments

- Pathology reports, including reports with negative findings
- Bone marrow biopsies
- Histology reports
- Cytology reports
- Hematology reports
- Autopsy reports
- Pathology logs
- Pathology appointment registers

Most newly diagnosed cancer patients have a biopsy or surgical procedure for which a pathology report is written identifying and classifying the excised specimen. All pathology reports, along with the clinical summary, should be read to identify cases. Cases in which only specimens were reviewed by the reporting hospital may never have a medical record. The coded final histologic diagnoses (in SNOMED) should be reviewed. Sometimes a programmer can prepare a list containing only malignancies.

A <u>negative</u> pathology or cytology report may be a hidden source for finding certain cases. If an excisional biopsy was performed in a physician's office and the patient was later referred to the hospital for additional treatment, the pathology report may be negative if no further cancer was detected. The case should still be reported to the State Registry by the hospital because the patient was referred to the hospital for further diagnosis or treatment (class of case 2).

- Example #1: A physician diagnoses a melanoma and performs the excisional biopsy in the office. The patient is then admitted to the hospital for a wide excision. The pathology report does not show any malignancy. Although the pathology report is negative, the case should be reported to the State Registry by the hospital because the patient was referred to the hospital for additional treatment.
- Example #2: A physician performs a lumpectomy for breast cancer in the office. The patient is later admitted to the hospital for a modified radical mastectomy. No residual tumor was noted on the pathology report. The hospital must report this case to the State Registry, even though the pathology report is negative.
- 2. <u>Health Information Management Department</u> (Medical Record Department)
  - Inpatient records
  - Outpatient records
  - Disease or diagnostic index
  - Computerized listings of specific cancer-related ICD-9-CM codes
  - Operation index
  - Admitting lists
  - Discharge lists

Health information management department personnel may assist in case identification in a number of ways. A regular listing of all cancer cases may be helpful in casefinding. Working with personnel responsible for assembly and analysis of records upon discharge may identify patients overlooked through other reviews. Coders could flag all medical records with malignant diagnoses for review by the Cancer Registrar. If feasible, direct review of all medical records by the cancer registrar assures more complete casefinding. Appendix C lists the ICD-9-CM codes that should be reviewed for eligible cases.

## 3. Bill and Insurance Department (Patient Accounts)

Print-outs listing cancer-related diagnostic codes

Hospital and/or departmental billing systems use diagnostic codes for billing purposes. Computerized billing systems may be used to generate lists of cancer-related diagnostic codes. See Appendix C of this manual for a list of cancer-related codes. Cancer registrars should work with billing department personnel to assess the capabilities of the system and develop the parameters of the report. The process may involve the computer vendor.

## 4. Radiology Department

- Radiation therapy treatment summaries
- Radiation therapy new patient listings
- Radiation therapy log
- Radiation therapy schedule
- Radiation oncology records

- Nuclear medicine reports
- Nuclear medicine log
- Nuclear medicine schedule
- Diagnostic radiology reports
- Scans

The radiation therapy department can be an important source of casefinding since many patients are treated solely as outpatients and may be missed by other casefinding methods. Radiology records should be made available to the person responsible for casefinding, by either providing copies of the reports or permitting access to the radiation therapy department's patient records. A periodic review of the department's therapy log or schedule will serve as a quality control check and help ensure completeness of casefinding.

## 5. Outpatients/Clinics/ER

- Ambulatory/outpatient surgery records
- Day surgery logs
- Outpatient scheduling logs
- CPT codes on outpatient records
- Emergency room records/logs
- ENT (ear, nose, throat) clinic records
- Eye clinic records
- Skin (melanoma, others) clinic records
- Mycosis fungoides clinic records
- OB/GYN clinic records
- AIDS/Kaposi's sarcoma clinic records

If outpatient records are not filed in the medical record department, arrangements should be made with the applicable departments and clinics for access to the patient records at a mutually convenient time.

## 6. Cancer Conference/Tumor Board

The cancer committee of a hospital is responsible for conducting cancer conferences (tumor boards) to provide consultative services to patients and to educate the medical staff. Attendance at these conferences or review of minutes may identify additional cancer patients.

## 7. Other Sources of Casefinding

- Operation/surgery log
- Operation/surgery schedule
- Oncology/Hematology records
- Chemotherapy logs
- Staff physician's office

## **Preventing Duplicates**

All cancer patients who have been identified by any of the methods described above should be checked against cases in the suspense system (Chapter 2, section D) and the patient index (Chapter 2, section F). If a patient's name is found in either of these places with the same primary cancer, the case has been identified previously and should not be added to the database. These patients may be readmissions for additional treatment, recurrence, progression of or persistent disease, or follow-up.

The information obtained through casefinding should be preserved and used to help complete the abstract (if the case was found in the suspense system) or to complete follow-up (if the case was found in the patient index), if applicable.

## D. SUSPENSE SYSTEM

#### Definition

A suspense system is a file or a list of cancer cases that have been identified but have not yet been completely entered, abstracted, or accessioned into the registry. The file or list serves as a method for keeping track of identified cancer patients until the abstracts are complete.

## **Purpose**

The suspense system has two functions:

- To avoid duplicate case identification, and;
- To serve as a quality control check to assure that over a period of time, all identified cases have been abstracted.

## Organization

For convenience in duplicate checking, the suspense system should be arranged alphabetically by month of case identification.

Patient data should include:

Patient name
Date of diagnosis
Medical record number
Cancer primary site

A paper abstract with the above information could be used as the suspense system, or an index card could be completed. The abstracts or cards should be filed alphabetically.

If the patient index described in Section F. is maintained on cards, these cards could be partially completed and used in a suspense file. Once the case is fully abstracted, the card in the suspense file could be moved to the alphabetic patient index and the rest of the information completed.

A suspense system can also be set up in the Rocky Mountain Cancer Data System (RMCDS) program. As much information as is initially known about the patient is entered (e.g., name, medical record number, admission date, etc.). In the "Suspense" field, code 1 is entered to indicate the case is in suspense. Records with suspense code 1 are excluded when extensive edits are applied. When the full case is later abstracted, the suspense code 1 should be changed to zero (0) and the edits should be applied. A list can be printed at any time of all patients with suspense code 1 to ensure abstracting has been completed for all cases in the suspense file.

#### E. ACCESSION REGISTER

## Definition

The accession register is an annual, sequential listing of all reportable cases included in a hospital's cancer registry. It serves to identify, count, and evaluate the annual caseload. The register can be used to audit other registry files, monitor casefinding, assess the workload, and verify patient identification.

#### **Description**

The following items should be included in the accession register:

#### 1. Accession number

The first four digits of the accession number should specify the year that the patient was first seen at the reporting hospital for the diagnosis and/or treatment of cancer following the registry's reference date. The last five digits are a number each case is assigned in sequential order, beginning with 00001 at the start of each new calendar year. Detailed instructions on accession numbers can be found in Chapter 5 in item 12.

## 2. Sequence number

Sequence numbers indicate the chronological order of the diagnoses of independent, primary malignancies that occur over the patient's lifetime. Detailed instructions on sequence numbers can be found in chapter 5 in Item 13.

- 3. Patient name
- 4. Primary site
- 5. Date initial diagnosis (or date first seen at the reporting institution)
- 6. Class of case (optional; see Item 17 in Chapter 5 for further information)

A sample page follows, but the hospital should design their accession register according to their own needs.

Accn. Year & Number	Seq.	Name	Primary Site	Date of Diagnosis	Class
200100001	<del>00</del> 01	Brown, John Q.	prostate	01/02/01	1
200100002	00	Smith, Susan	lung	01/15/01	0
199700150	02	Jones, Mary (patient's first primary was in 1997)	breast	02/07/01	1
200100003	00	Green, George	pancreas	03/24/01	2
200100001	02	Brown, John Q. (patient's first primary was 200100001)	kidney	04/08/01	1
200100004	00	Washington, Martha	colon	04/21/01	0

An explanation of how the registry would assign the accession numbers in the 2001 table above follows:

- 1. 200100001-00 (for the patient's first primary malignancy)
- 2. 200100002-00
  - 3. 199700150-02 (A patient whose first primary was entered in the registry in 1997 retains the original accession number and only the sequence number changes.)
- 4. 200100003-00
- 5. 200100001-02 (For the patient's second of two primaries in 2001, the patient's original accession number remains the same, but the sequence number for his first primary must be changed from 00 to 01.)
- 6. 200100004-00

The final (highest) accession number for a year will not necessarily be the total number of new cases that year. Patients admitted with new primaries and who had accession numbers assigned in a previous year will be listed but using the original number and therefore will not be counted in the current year's sequence of accession numbers.

#### F. PATIENT INDEX

#### Definition

The patient index is a complete alphabetical file or list of all patients, living or dead, identified and reported by the hospital since the reference date (starting date for reporting). Before a patient is added to the registry, the patient index should be checked to see if the patient has already been accessioned.

## Description

The following data items must be included in the patient index:

Name

Date of birth

Sex

Medical record number

Accession number

Date of death

Sequence number (for each primary site)

Date of diagnosis (for each primary site)

Laterality (for each primary site)

Site (for each primary site)

Histology (for each primary site)

Below is a sample patient index entry, but the hospital should design their file according to their own needs.

Name:		DOB:	Sex:
MR#:	_Accn No:	Date of Death:	
		Laterality:	
		Laterality:	
		Laterality:	
ICD-O-3 Site:	Histology:		

There should be only ONE entry or card per patient in the patient index. All independent primaries in the same patient are included on the same entry or card. The index should be maintained in alphabetic order and be retained indefinitely.

## G. FILING

Hospitals reporting by paper abstracts should keep the **original** abstract form and submit a **copy** of the abstract form to the State Cancer Registry (see Chapter 3). The most efficient filing system for hospitals reporting on paper abstracts is filing all cases in ascending numerical order by the first two digits of the primary site code.

Example: All patients with cancer of the small intestine (C17.\_) are filed before all patients with cancer of the colon (C18.\_).

Within each site, cases are separated by accession year. Within each accession year, cases are filed alphabetically.

Example: All patients with colon cancer in 1994 will be filed alphabetically behind all patients with colon cancer in 1993.

The file of abstracts in site order could serve as a primary site index, making records more easily retrievable for studies.

The original abstract, any copies of it, and associated documentation must be regarded as confidential medical records and their storage should comply with applicable hospital and state regulations for confidentiality and security of records. Abstracts should be retained indefinitely.

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## **CHAPTER 3: REPORTING**

#### A. OVERVIEW

This chapter explains the forms used in reporting, the cases and types of diagnoses to be reported, who should submit abstracts, when abstracts should be submitted, and how they should be submitted.

## **B. FORMS USED IN REPORTING**

#### 1. Hospital Abstract

The "Hospital Abstract," a form for reporting information about reportable cases, is provided in the front of Chapter 5 in this manual. Two versions of the form are provided for use based on diagnosis year as designated in the heading of each form ("Cases Diagnosed Through 12/31/2003" and "Cases Diagnosed 01/01/2004 and Later"). Non-computerized registries should abstract all reportable cases on the applicable version of the form. Computerized registries may use the form to submit reportable nonanalytic cases that are not abstracted into their registry systems.

Forms may be obtained, free of charge, by calling or writing the State Cancer Registry.

Marsha Lundy Office: (317) 233-7158 Indiana State Cancer Registry Fax: (317) 233-7722

Indiana State Department of Health E-mail: mlundy@isdh.state.in.us

2 North Meridian Street, Section 7-D

Indianapolis, IN 46204-3010

## 2. Correction and Follow-Up Form

Chapter 6 of this manual includes a "Correction and Follow-Up Form" and instructions for completing it. Corrections or annual follow-up data on previously submitted Hospital Abstracts may be reported on this form. Hospitals should make copies of the form from the sample in the manual.

## 3. Correction Form for Multiple Patients

Chapter 6 also includes a "Correction Form for Multiple Patients" and instructions for completing it. Hospitals should make copies of the form from the sample in the manual.

## C. CASES TO REPORT TO THE STATE REGISTRY

## 1. General Requirements

- All confirmed cases of reportable tumors <u>diagnosed and/or initially treated</u> in Indiana must be reported to the State Cancer Registry, as specified in this section. Reportable diagnoses are listed in Appendix B.
- Confirmed cases include clinically diagnosed patients (not microscopically confirmed) as well as microscopically confirmed diagnoses. If a recognized medical practitioner documents that a patient has cancer, the diagnosis is reportable. Terms that constitute a clinical diagnosis can be found in Chapter 4.
- Reportable cases include inpatients and outpatients (including hospital-affiliated ambulatory care settings).

## 2. Required Cases

a. In situ and frank malignancies – those with an *International Classification of Diseases for Oncology, Third Edition,* 2000 (*ICD-O-3*) fifth digit behavior code of /2 or /3. These diagnoses appear on the Reportable List of Malignancies in Appendix B.

## Exceptions (Not Reportable):

- Preinvasive cervical neoplasia (CIS and CIN III) diagnosed 01/01/2003 or later;
- Prostatic intraepithelial neoplasia, grade III (PIN III) diagnosed 01/01/2003 or later;

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Basal cell and squamous cell carcinoma of skin (ICD-O-3 primary site codes C44.0-C44.9 with histology codes 8000-8110) diagnosed 01/01/2003 or later.

- b. If diagnosed before 01/01/2003, basal cell and squamous cell carcinoma of skin (*ICD-O-3* primary site codes C44.0-C44.9 with histology codes 8000-8110) that meets at least one of the following conditions at the time of diagnosis:
  - (1) Primary tumor more than 5 centimeters in greatest dimension;
  - (2) Primary tumor that has invaded deep extradermal structures such as cartilage, skeletal muscle, or bone;
  - (3) Primary tumor with regional node metastases;
  - (4) Primary tumor with metastasis to distant sites.
- c. Basal cell and squamous cell carcinoma (*ICD-O-3* histology codes 8000-8110) that originates in a mucous membrane site:
  - Lip C00.0 C00.9 ■ Anus C21.0
  - Labia C51.0 C51.1
  - Clitoris C51.2
  - Vulva C51.8 C51.9
  - Vagina C52.9
  - Prepuce C60.0
  - Penis C60.1 C60.9
  - Scrotum C63.2
- d. Juvenile astrocytoma, listed as 9421/1 in *ICD-O-3*, is required and should be reported as 9421/3.
- e. All benign and borderline (behavior codes /0 and /1) intracranial and central nervous system tumors diagnosed January 1, 2004 or later. (*ICD-O-3* primary site codes C70.0-C72.9, C75.1-C75.3.)
- f. Analytic cases (see Item 28 in Chapter 5 for further information on analytic and nonanalytic cases). Analytic cases include the following:
  - (1) All new malignancies diagnosed at the reporting hospital on or after January 1, 1987 (class of case 0).
  - (2) All malignancies initially diagnosed <u>and</u> treated at the reporting hospital for all or part of the first course of treatment on or after January 1, 1987 (class of case 1).
  - (3) All malignancies initially treated at reporting hospital for all or part of the first course of treatment on or after January 1, 1987 (class of case 2).

This includes patients who previously have been diagnosed with a cancer prior to January 1, 1987 and have a <u>new primary malignancy diagnosed at the reporting hospital on or after January 1, 1987. (Only the new malignancy diagnosed on or after January 1, 1987 must be reported to the State Cancer Registry.) Do not report the malignancy diagnosed before January 1, 1987.</u>

- g. Nonanalytic class of case 3 diagnosed on or after January 1, 1987. Class 3 includes cases first diagnosed elsewhere and all of the first course therapy elsewhere. The reporting institution is treating the recurrence or progression of a malignancy diagnosed January 1, 1987 or later.
- h. Nonanalytic class of case 4 diagnosed on or after January 1, 1987. Class 4 includes cases first diagnosed and/or first course of therapy at the reporting institution before the registry's

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reference date. Class 4 cases would be reported only by a registry with a reference date later than 1987.

- Example 1: Hospital A changed their reference date from 1987 to 1992. In 1993, a patient is admitted who was diagnosed with a melanoma at Hospital A in 1990 and has returned for a recurrence. The case is class 4 for the hospital and should be reported to the State Registry in 1993 if not previously reported when diagnosed.
- Example 2: Hospital A changed their reference date from 1987 to 1992. In 1993, a patient is admitted with a second primary. The first primary, diagnosed at Hospital A in 1990, is class of case 4 for the hospital and should be reported to the State Registry in 1993 if not previously reported when diagnosed.
- i. Patients first diagnosed at autopsy (Nonanalytic class of case 5).
- Patients diagnosed and treated only in a staff physician's office (Nonanalytic class of case 6). Reportable by the hospital only if the hospital collects class 6 cases. Otherwise, reportable by the physician's office.
- k. The types of cases list below <u>are</u> reportable to the State Registry, though not reportable by ACoS standards. Since documentation for these cases may be limited, report all information available either in your usual format, by paper abstract, or by sending copies of pertinent medical record documentation.
  - (1) Pathology-only cases (Nonanalytic class of case 7).
  - (2) Patients seen in consultation to confirm a diagnosis or treatment plan. This includes cases where a patient is seen only once at the reporting hospital with an abnormal or positive-appearing x-ray or scan, but the patient never returns for any work-up, confirmation of diagnosis, or treatment.
    - Example: A patient comes to the institution for a second opinion. Staff physicians order diagnostic tests and support the original treatment plan. The patient returns to the other institution for treatment.

## D. CASES NOT REQUIRED

1. Cases with an *International Classification of Diseases of Oncology, Third Edition*, 2000 (*ICD-O-3*) fifth digit behavior code of /0 (benign) or /1 (uncertain or borderline), which are the codes for precancerous conditions or benign tumors.

## Exceptions (Reportable):

- Juvenile astrocytoma, listed as 9421/1 in ICD-O-3, is required and should be reported as 9421/3.
- All benign and borderline intracranial and central nervous system tumors diagnosed January 1, 2004 or later are reportable. (ICD-O-3 primary site codes C70.0-C72.9, C75.1-C75.3.)
- 2. If diagnosed 01/01/2003 or later, all basal cell and squamous cell carcinoma of skin (*ICD-O-3* primary site codes C44.0-C44.9 with histology codes 8000-8110).
  - If diagnosed before 01/01/2003, basal cell and squamous cell carcinoma of skin that are in situ or that are invasive and 5 centimeters or less in greatest dimension with no lymph node or distant metastasis.

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3. Analytic cases (class of case 0, 1, 2) who were first diagnosed or first treated at the reporting institution on or after January 1, 1987 and return to the hospital for:

- a. A recurrence of that same primary;
- b. Subsequent treatment;
- c. Progression of recurrent disease (disease free period); or
- d. Continued or persistent disease (never disease free).

**Note:** An abstract would have been submitted when the patient was first diagnosed or first treated. Once a case has been accessioned into a registry, it is <u>not</u> re-accessioned or reported if the patient returns to the hospital for that <u>same</u> primary.

- 4. Nonanalytic class of case 3 diagnosed before January 1, 1987. Class 3 includes cases first diagnosed elsewhere and all of the first course therapy elsewhere. If the reporting institution is treating the recurrence or progression of a malignancy diagnosed before January 1, 1987, the case should not be reported to the state.
- 5. Nonanalytic class of case 4 diagnosed before January 1, 1987. Class 4 includes cases diagnosed and/or first course of therapy at the reporting institution before the registry's reference date. Patients with the following situations would be non-reportable class of case 4:

Patients first diagnosed before January 1, 1987 who:

- a. Received no treatment after being diagnosed;
- b. Received first course of treatment before January 1, 1987;
- c. Received first course of treatment <u>before</u> January 1, 1987 and subsequent treatment on or after January 1, 1987;
- d. Received first course of treatment <u>before</u> January 1, 1987 and had a recurrence of that same primary on or after January 1, 1987.
- 6. Patients who receive transient care to avoid interrupting a course of therapy started elsewhere. Please verify with the State Cancer Registry that such patients who are Indiana residents have been reported by the other facility.
  - Example 1: A patient is visiting relatives in the area. The oncology department at the reporting facility dispenses the scheduled chemotherapy.
  - Example 2: Another institution sends a patient to the reporting facility because of equipment failure. The reporting facility administers the radiation therapy until the equipment is repaired. The patient returns to the original institution to complete therapy.
- 7. Patients with active cancer who are admitted for an unrelated medical condition. Please verify with the State Cancer Registry that such cases have been reported.
  - *Example:* A patient with active prostate cancer enters the reporting institution's cardiac care unit for cardiac care only.
- 8. Patients with a history of cancer who currently have no evidence of the disease. Please verify with the State Cancer Registry that such cases have been reported.
- 9. Patients admitted to a designated hospice unit or home care service. Please verify with the State Cancer Registry that such cases have been reported.
- 10. Patients admitted for terminal supportive care only. Please verify with the State Cancer Registry that such cases have been reported.
- 11. Class of case 8 (diagnosed by death certificate only). The State Cancer Registry will collect cancer data on these patients after all reasonable efforts to obtain information from a health care provider have failed.

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- 12. Residents of a foreign country.
- 13. Annual follow-up on all cases (optional reporting).

14. Hospitals may abstract cases that are not required by the State Registry, but are important for their own clinical, administrative, management, or marketing purposes. These patients often receive services and use the resources of the hospital (e.g., chemotherapy, radiation, lab tests, etc.). These cases should <u>not</u> be reported to the State Registry. Examples include non-reportable localized basal cell carcinoma of the skin and class 4 cases diagnosed before 1987.

## E. DATA ITEMS TO REPORT

## 1. Analytic Cases

Required and optional data items to report to the State Registry for analytic cases are identified in Chapter 5 of this manual. The items are listed in a table on pages 31-36 of Chapter 5 and are presented in the pages following the table with descriptions, codes, formats, definitions, rules, and instructions.

## 2. Reportable Nonanalytic Cases

Since hospitals may have limited information about class 3 and 4 cases (reportable if diagnosed after January 1, 1987), a minimal data set for these cases is presented in the table below. The item numbers match those in chapter 5 and represent the order of the items in the paper abstract. Apply the codes, definitions, and rules in chapter 5 for these items and record them in either the paper or a computerized abstract. If the information for an item is not available, leave the item blank or code it according to the vendor's instructions for "unknown."

No.	Item	Notes
1.	Reporting hospital	ID number
2.	Abstracted by	Abstractor's initials
3.	Type of reporting source	
4.	Patient last name	
5.	First name	
6.	Middle name	
7.	Maiden name	If known
8.	Alias	If known
9.	Street address at diagnosis	Not current address; if unknown, record "unknown"
11.	City/town at diagnosis	Not current city/town; if unknown, record "unknown"
12.	State at diagnosis	Not current state; "ZZ" if unknown
13.	ZIP code at diagnosis	Not current ZIP; if unknown, record 9's
14.	County at diagnosis	Not current county; if unknown, record 9's
15.	Social Security Number	If known; if unknown, record 9's
16.	Date of birth	If known; if unknown, record 9's
18.	Medical record number	
19.	Sex	
20.	Race/Spanish origin	At least race, if known
23.	Other primary tumor(s)	If known
24.	Date of first contact	At your hospital for this tumor
25.	Accession year this primary	

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No.	Item	Notes
26.	Hospital accession number	If assigned
27.	Sequence number	
28.	Class of case	Class 3 or 4
29.	Referred from	If known
31.	If diagnosed elsewhere, record where	Name, phone number, and address of diagnosing physician, lab, clinic, etc., if known
32.	Date of initial diagnosis	If unknown, estimate year
33.	Primary site	Not metastatic site
34.	Laterality	For original, primary site, if known
35.	Diagnostic confirmation	If known
36.	Histology/behavior/grade	For original, primary site, if known
37.	Description of diagnosis	Narrative text of site and histology, if known
69.	Description of treatment	Narrative text, if known
70.	Date of last contact/death	
71.	Vital status	
72.	Cancer status	If known
73.	Remarks	Any other pertinent information

## F. WHO SHOULD SUBMIT REPORTS

The hospital that <u>first diagnoses</u> a case (class of case 0 or 1; class of case 4 if diagnosed in 1987 or later) is responsible for submitting an abstract to the State Cancer Registry.

A hospital that performs part or all of the <u>first course treatment</u> (class of case 1 or 2; class of case 4 if diagnosed in 1987 or later) is responsible for submitting an abstract to the State Cancer Registry.

A hospital that treats recurrence or progression of a malignancy first diagnosed elsewhere in 1987 or later and all of first course of treatment performed elsewhere (class of case 3 diagnosed in 1987 or later) is responsible for submitting an abstract to the State Cancer Registry.

The staff physician's office is considered an extension of the hospital. Cases of patients who are diagnosed or treated in a staff physician's office and referred to the hospital for definitive therapy must be reported as though they were diagnosed at the hospital. If these patients were referred to another institution for their first course of treatment, then their cases need not be included. Patients diagnosed <u>and</u> treated only in a staff physician's office (class of case 6) are to be reported if such cases are collected by the hospital. If not reported by the hospital, class 6 cases must be reported by the physicians' offices.

When the distinction between a hospital-based department and a free-standing facility cannot readily be made (e.g., a radiation therapy group practice versus a hospital unit) the ownership of the medical record should be used to determine whether a case must be reported by the hospital. The owner of the medical record is responsible for reporting the case to the State Cancer Registry.

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#### G. WHEN TO SUBMIT REPORTS

Facilities must complete and submit reports of confirmed cases of reportable tumors to the State Cancer Registry no later than six (6) months following the date the patient comes under the care of the reporting facility. Facilities should report on a schedule based on the size of their annual caseload. The <u>minimum</u> reporting requirements for each caseload range is provided in the table below. More frequent reporting is encouraged so that the State database remains as current as possible for analytic purposes.

REPORTING SCHEDULE					
Average Number of Cases Minimum Frequency for Diagnosed per Year Reporting to the State					
1-59	Once per year				
60-149	Quarterly				
150-299	Every other month				
≥ 300	Every month				

#### H. HOW TO SUBMIT REPORTS

## 1. Hospital Using Paper Forms

- a. Hospitals should submit reports to the State within the time frame described in this chapter, using the "Hospital Abstract" form (copy in Chapter 5) designed and approved by the State Cancer Registry.
- b. Attach a copy of the pathology report to the abstract form. State Cancer Registry staff need the reports to substantiate the codes.
- c. When sending in more than one abstract for multiple tumors on a patient, do not staple abstracts on different tumors together, as they may be overlooked. <u>Do</u> staple copies of medical record documentation about the reported tumor to the applicable abstract.
- d. The hospital should make a <u>legible</u> copy of the original abstract and mail the copy to the State Cancer Registry, keeping the original at the hospital. Illegible abstracts will be returned to the hospital.
- e. Ensure that abstracts are treated with the same level of security and confidentiality as the medical record. The abstracts are abbreviated medical records and should be treated as such. A full discussion of confidentiality is found in Chapter 8 of this manual.
- f. The hospital should keep a record of abstracts mailed to the State Cancer Registry, noting the date and number submitted. The State Cancer Registry personnel will keep track of the number of abstracts and date received from each hospital.
- g. Envelopes containing copies of the abstracts should be carefully sealed and labeled "CONFIDENTIAL MEDICAL INFORMATION." The envelope should be clearly addressed:

Indiana State Cancer Registry Indiana State Department of Health 2 North Meridian Street, Section 7-D Indianapolis, IN 46204-3010 Reporting Chapter 3

# 2. Hospitals With Computerized Systems

a. Hospitals with computerized registries should submit reports to the State Cancer Registry in an acceptable, machine-readable format (RMCDS format for hospitals using RMCDS software and NAACCR format for those using other systems) within the time frame described in this chapter.

- b. Make sure all cases abstracted since the previous submission are selected for each new submission. Selecting cases by a range of accession numbers will omit patients with an earlier accession number who have a new primary. Contact your software vendor for procedures to ensure all cases are reported to the State Cancer Registry.
- c. Submitting on Diskettes
  - (1) Make sure the label on the diskette identifies the hospital name and city, 3-digit ID number (see Appendix D), vendor name (ERS, IMPAC, IMPATH, RMCDS), names of files on the disk, and a brief description of what records are included.

Example: Community-Munster, #018, ERS, State.dat, April - May 2003

(2) After appropriate back-up procedures, the diskettes should be packaged in containers designed for mailing diskettes. The hospital may wish to insure the package. The package should be carefully sealed and labeled "CONFIDENTIAL MEDICAL INFORMATION." The package should be clearly addressed:

Indiana State Cancer Registry
Indiana State Department of Health
2 North Meridian Street, Section 7-D
Indianapolis, IN 46204-3010

- d. Submitting by E-Mail
   Contact the State Cancer Registry to obtain procedures for submitting data by e-mail.
- e. Ensure that the contents of computerized abstracts are treated with the same level of security and confidentiality as the medical record. The abstracts are abbreviated medical records and should be treated as such. A full discussion of confidentiality is found in Chapter 8 of this manual.
- f. The hospital should keep a record of cases submitted to the State. The State Cancer Registry personnel will keep track of the date, number of disks, and number of cases received from each hospital.

# **CHAPTER 4: GENERAL DEFINITIONS FOR CODING**

#### A. INTRODUCTION

The State Cancer Registry uses definitions published by national standard-setting organizations in order to ensure that its instructions and the data collected are consistent with those from other registries. The standard-setting organizations include the American College of Surgeons, Commission on Cancer (ACoS/CoC); the North American Association of Central Cancer Registries (NAACCR); and the National Cancer Institute's SEER (Surveillance, Epidemiology, and End Results) program.

#### **B. GUIDELINES FOR INTERPRETATION OF TERMINOLOGY**

The overall priority for using information to determine tumor involvement is pathological, operative, then clinical findings. The medical practitioner may use ambiguous terms when describing a clinical diagnosis or extent of disease in relation to tumor invasion of an organ or structure, especially when there is no cytologic or histologic proof of disease extension. When there are questions concerning terminology, consult with a physician or pathologist. The following lists should be used when the terminology is vague or ambiguous.

# Terms That Indicate Clinical Diagnosis or Tumor Involvement/Extension

- adherent to
- apparent
- apparently
- appears to
- · comparable with
- compatible with
- consistent with
- contiguous/continuous with
- encroaching upon
- extension to, into, onto, or out onto
- favor(s)
- · features of
- fixation (to another structure)
- fixed (involvement of other organ/tissue)
- impending perforation of <sup>2</sup>
- impinging upon <sup>2</sup>
- impose, imposing on <sup>2</sup>
- incipient invasion
- induration (for breast cases)
- infringe, infringing<sup>2</sup>
- into
- intrude
- invasion to, into, onto, or out onto

- malignant appearing
- matted (for lymph nodes only)
- most likely
- neoplasm (only for C70.0-C72.9, C75.1-C75.3 diagnosed 01/01/04 and later)
- obliterate
- onto
- out onto
- overstep<sup>2</sup>
- presumed
- probable
- probably
- protruding into (unless encapsulated)
- suspect
- suspected
- suspicious (for) <sup>1</sup>
- to
- tumor (only for C70.0-C72.9, C75.1-C75.3 diagnosed 01/01/04 and later)
- violate
- typical of
- up to

Example: A chest x-ray is consistent with a carcinoma of the right upper lobe. Final diagnosis is probable carcinoma of the right lung. The case should be abstracted and reported.

<sup>1</sup> **Exception:** If a cytology specimen is reported as "suspicious," do not interpret this as a diagnosis of cancer unless it is confirmed by a positive biopsy or a physician's clinical assessment.

<sup>&</sup>lt;sup>2</sup> These terms are considered involvement by the SEER Program and non-involvement by the Statistical Analysis and Quality Control Center at Fred Hutchinson Cancer Research Center in Seattle, WA. Consult the attending physician regarding these terms.

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# **Terms That Do Not Indicate Clinical Diagnosis or Tumor Involvement**

- abuts
- along side
- · approaching
- approximates
- attached
- borders on
- cannot be excluded/ruled out
- efface, effacing, effacement
- encased, encasing
- encompass(ed)
- entrapped
- equivocal
- extending up along
- extension over
- extension to without invasion/involvement of

- kiss, kissing
- matted (except for lymph nodes)
- next to
- possible
- potentially malignant
- questionable
- reaching
- rule out
- suggests
- up along
- up over
- · very close to
- without perforation of
- worrisome

*Example:* The final diagnosis is possible carcinoma of the breast. This case should not be abstracted and reported

# **CHAPTER 5: CODING INSTRUCTIONS**

#### **OVERVIEW**

The abstract is a summary of pertinent information about the patient, the cancer, the treatment, and outcome. Facilities with non-computerized registries must report such information on the <u>Hospital Abstract</u> located at the beginning of this chapter. Two versions of the form are provided for use based on diagnosis year as designated in the heading of each form ("Cases Diagnosed Through 12/31/2003" and "Cases Diagnosed 01/01/2004 and Later"). The abstract is used to collect the following three categories of information:

## **Patient and Hospital Identification**

This includes data items numbered 1 through 31. The data relate primarily to demographic information about the patient and hospital-specific information.

## **Cancer Identification**

This includes data items numbered 32 through 54. The data relate primarily to information about the patient's tumor or cancer.

#### Treatment Data

This includes treatment data in items numbered 55 through 69 and follow-up information in items numbered 70 through 72.

Chapter 5 explains how to complete each item within the three categories. Rules and codes for recording the information are consistent with the *Facility Oncology Registry Data Standards (FORDS)* to the extent possible and apply to both paper and computer abstracting unless they conflict with an alternative software vendor's instructions. As with the *FORDS*, abstracters should use the rules and codes in this manual only for cases diagnosed January 1, 2003 and later unless instructed otherwise. Chapter 3, Section C., page 17 lists the types of cases to be reported on an abstract.

## WHEN TO ABSTRACT A CANCER CASE

- Cancer case information should be abstracted after complete work-up, cancer staging, and planned first course of treatment have been initiated. The first course of treatment is generally initiated within four months after the cancer is initially diagnosed. For further information on "First Course of Treatment," see pages 177-179 in this chapter. With the exception of early deaths, cases should not be abstracted less than four months after diagnosis.
- 2. Cases are due at the State Cancer Registry no later than six months following the date the patient comes under the care of the reporting facility.
- 3. Follow-up items 70 through 72 are required and should be completed at the time the rest of the case is abstracted. Subsequent, annual follow-up information is optional, but may be reported if desired. See Chapter 6 for details on how to submit annual follow-up information at a later date.
- 4. There is no time limit for making revisions that give better information about the <u>original</u> diagnosis or stage. Data should be coded using the most accurate information available for an up-to-date and factual database. Over time, information that was missing when the case was first abstracted may be added to the patient's medical record. Such additions may contain new information. The latest or most complete information available should be used. Thus, it is acceptable to change the primary site, histology, and extent of disease (staging data) as information becomes more complete.

**Note:** This does not mean that if the patient's disease progresses, you should change the original stage to a higher stage. Staging should reflect only information available through completion of

Coding Instructions Chapter 5

surgery(ies) in the first course of treatment or within four months of diagnosis in the absence of disease progression, whichever is longer. However, if the original stage is later found to be incorrect, it would be appropriate to change the stage to the correct code.

#### GENERAL ABSTRACTING INSTRUCTIONS AND DEFINITIONS

- Each primary cancer should be abstracted only once by a facility. However, if a patient is
  diagnosed with more than one primary cancer, whether simultaneously or at different times, a
  separate abstract must be completed for each primary cancer.
- 2. Enter all information accurately. Entries on the paper abstract should be printed legibly.
- 3. For the numbered items in Chapter 5, the numbers correspond with those on the paper abstract provided at the beginning of the chapter. Unnumbered items are either optional or are items completed at the State Registry.
- 4. Items that are <u>not</u> required by the State Registry are identified as optional in the item heading and the headings are shaded in the same manner as in the paper abstract.
- 5. The following terms are used throughout this chapter to indicate type, justification, and length of data fields:

Numeric: The field will accept numbers only. Alphabetic: The field will accept letters only.

Alphanumeric: The field will accept either letters or numbers, but no special characters.

Text: The field will accept any letter, number, symbol, or space.

Left-Justified: Data are to be entered starting at the first space toward the left. Leave unused

spaces blank unless otherwise instructed.

Right-Justified: Data are to be entered so that the last character falls in the last space on the right in

the field. Leave unused spaces blank or zero fill, as directed.

Length: Length refers to the number of characters in each data field.

6. The following abbreviations are used throughout Chapter 5:

ACoS	American College of Surgeons
AJCC	American Joint Committee on Cancer
CDC	Centers for Disease Control and Prevention
CoC	Commission on Cancer
DAM	Data Acquisition Manual (from the Commission on Cancer, ACoS), revised September 1994
FORDS	Facility Oncology Registry Data Standards (from Vol. II, Standards of the Commission on Cancer, ACoS), revised 2002
ROADS	Registry Operations and Data Standards (from Vol. II, Standards of the Commission on Cancer, ACoS), revised January 1996
ICD-0-2	International Classification of Diseases for Oncology, Second Edition, 1990
ICD-0-3	International Classification of Diseases for Oncology, Third Edition, 2000
JCAHO	Joint Commission on Accreditation of Healthcare Organizations
NAACCR	North American Association of Central Cancer Registries
RMCDS	Rocky Mountain Cancer Data Systems
SEER	Surveillance, Epidemiology, and End Results (National Cancer Institute program)

7. The data sets for each item are identified in the item headings in Chapter 5. "N/A" indicates the item is not included in either an ACoS or a State Registry data set. The data sets addressed in Chapter 5 are defined below.

# **DEFINITION OF DATA SETS**

(Revised for cases diagnosed 01/01/2008 and later.)

# 1. American College of Surgeons (ACoS)

Commission-approved programs must record the required (R) data set items using the codes and definitions specified in the *FORDS*.

# 2. National Program of Cancer Registries (NPCR)

Required (R) data elements for state cancer registries participating in the National Program of Cancer Registries of the Centers for Disease Control and Prevention. RH indicates data elements that are historically collected and currently transmitted. R^ indicates text requirements that may be met with one or several text block fields. RS indicates data elements that are required for specific sites only. D identifies data elements that are derived from other elements by computer algorithm.

# 3. Indiana State Cancer Registry (ISCR)

- a. Required Data Set (R) must be reported to the State Cancer Registry. (RS indicates the data element is required for specific sites only.)
- b. Optional Data Set (O) are not required but may be of interest to specific institutions or groups.

# **COMPARISON OF DATA SETS**

ITEM	NAACCR Item #	ACoS	NPCR	ISCR
PATIENT IDENTIFICATION				
Accession numberHospital	550	R		R
Sequence numberHospital	560	R		R
Year first seen for this primary	620			R
Medical record number	2300	R	R	R
Military medical record number suffix	2310	R		
Social Security number	2320	R	R	R
Last name	2230	R	R	R
First name	2240	R	R	R
Middle name	2250	R	R	R
Maiden name (if available)	2390		R	R
Alias (if available)	2280		R	R
Patient address (number and street) at diagnosis	2330	R	R	R
Patient address at diagnosis – supplemental (if available)	2335	R	R	R
City/town at diagnosis	70	R	R	R
State at diagnosis	80	R	R	R
Postal code at diagnosis	100	R	R	R
County at diagnosis	90	R	R	R
Patient address (number and street) – current	2350	R		0
Patient address current – supplemental	2355	R		0
City/town – current	1810	R		0
State – current	1820	R		0
Postal code – current	1830	R		0
County – current	1840			0
Census tract 2000 (completed by the State Registry)	130		R	R
Census tract certainty 2000 (completed by the State Regi	stry) 365		R	R

ITEM	NAACCR Item #	ACoS	NPCR	ISCR
Telephone	2360	R		
Date of birth	240	R	R	R
Birthplace (if available)	250	R	R	R
Age at diagnosis	230	R	R	R
Race 1-5	160-164	R	R	R
Spanish origin	190	R	R	R
Sex	220	R	R	R
Primary payer at diagnosis (if available)	630	R	R	R
Comorbidities and complications #'s 1-10	3110-3164	R		
NPI – Managing physician	2465	R		
Following physician	2470	R		0
NPI – Following physician	2475	R		
Primary surgeon	2480	R		0
NPI – Primary surgeon	2485	R		
Physician #3	2490	R		0
NPI – Physician #3	2495	R		
Physician #4	2500	R		0
NPI – Physician #4	2505	R		
Usual occupation (if available)	310		R	R
Usual industry (if available)	320		R	R
Type of reporting source	500		R	R
CANCER IDENTIFICATION				
Class of case	610	R	R	R
Facility referred from	2410	R		R
Facility referred to	2420	R		R
Suspense case				0
Where, if diagnosed elsewhere (text)				R
Date of first contact for this primary	580	R	R	R
Date of initial diagnosis	390	R	R	R
Primary site	400	R	R	R
Laterality	410	R	R	R
Histology	522	R	R	R
Behavior code	523	R	R	R
Grade/differentiation	440	R	R	R
Diagnostic confirmation	490	R	R	R
Ambiguous Terminology Diagnosis	442	R		
Date of Conclusive Diagnosis	443	R		
Date of Multiple Tumors	445	R		
Multiple Tumors Reported as One Primary	444	R		
Multiplicity Counter	446	R		
Primary site title (text)	2580		R^	R

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ITEM	AACCR Item #	ACoS	NPCR	ISCR
Histology title (text)	2590		R^	R
Dx procedure pathology (text)	2570		R^	R
STAGE OF DISEASE AT DIAGNOSIS		'		1
Date of surgical diagnostic & staging procedure	1280	R		R
Surgical diagnostic & staging procedure	1350	R		R
Surgical diagnostic & staging procedure at this facility	740	R		
Tumor size (Cases diagnosed through 12/31/03)	780	RH		RH
Description of size (text)				0
Regional nodes examined	830	R		R
Regional nodes positive	820	R		R
Site of distant metastasis #1	1090			R
Site of distant metastasis #2	1100			R
Site of distant metastasis #3	1110			R
SEER Summary Stage 2000 (For cases diagnosed through (Required by ACoS only in the absence of AJCC classification		RH	RH	RH
Substantiate stage (text)	2600		R^	R
CS tumor size (Cases diagnosed 01/01/04 & later)	2800	R	R	R
CS extension (Cases diagnosed 01/01/04 & later)	2810	R	R	R
CS tumor size/ext eval (Cases diagnosed 01/01/04 & later)	2820	R	R	R
CS lymph nodes (Cases diagnosed 01/01/04 & later)	2830	R	R	R
CS reg nodes eval (Cases diagnosed 01/01/04 & later)	2840	R		0
CS mets at dx (Cases diagnosed 01/01/04 & later)	2850	R	R	R
CS mets eval (Cases diagnosed 01/01/04 & later)	2860	R		0
CS site-specific factor 1 (Cases diagnosed 01/01/04 & later)	2880	RS	RS	RS
CS site-specific factor 2 (Cases diagnosed 01/01/04 & later)	2890	RS		RS
CS site-specific factor 3 (Cases diagnosed 01/01/04 & later)	2900	RS	RS	RS
CS site-specific factor 4 (Cases diagnosed 01/01/04 & later)	2910	RS		0
CS site-specific factor 5 (Cases diagnosed 01/01/04 & later)	2920	RS		0
CS site-specific factor 6 (Cases diagnosed 01/01/04 & later)	2930	RS		0
Derived AJCC T (autocoded) (If diagnosed 01/01/04 & later)	2940	D	D	0
Derived AJCC T descriptor (autocoded) (If diagnosed 01/01/04	& later) 2950	D	D	0
Derived AJCC N (autocoded) (If diagnosed 01/01/04 & later)	2960	D	D	0
Derived AJCC N descriptor (autocoded) (If diagnosed 01/01/04	& later) 2970	D	D	0
Derived AJCC M (autocoded) (If diagnosed 01/01/04 & later)	2980	D	D	0
Derived AJCC M descriptor (autocoded) (If diagnosed 01/01/04	1 & later) 2990	D	D	0
Derived AJCC stage group (autocoded) (If diagnosed 01/01/04	& later) 3000	D	D	0
Derived SS1977 (autocoded) (If diagnosed 01/01/04 & later)	3010	D	D	D
Derived SS2000 (autocoded) (If diagnosed 01/01/04 & later)	3020	D	D	D
Clinical T	940	R		0
Clinical N	950	R		0
Clinical M	960	R		0
Clinical stage group	970	R		0

ITEM	NAACCR Item #	ACoS	NPCR	ISCR
Clinical stage (prefix/suffix) descriptor	980	R		0
Stage by (clinical stage)	990	R		0
Pathologic T	880	R		0
Pathologic N	890	R		0
Pathologic M	900	R		0
Pathologic stage group	910	R		0
Pathologic stage (prefix/suffix) descriptor	920	R		0
Stage by (pathologic stage)	930	R		0
Dx procedures x-ray/scan (text)	2530		R^	0
Dx procedures lab tests (text)	2550		R^	0
History and physical (text)	2520		R^	0
Surgical staging procedures (text)	2560		R^	0
Diagnostic scope procedures (text)	2540		R^	0
FIRST COURSE OF TEATMENT		1	I	I
Surgical procedures (text)	2610		R^	R
Radiation beam (text)	2620		R^	R
Radiation other (text)	2630		R^	R
Chemotherapy (text)	2640		R^	R
Hormone (text)	2650		R^	R
Immunotherapy/BRM (text)	2660		R^	R
Other therapy (text)	2670		R^	R
Date of first course of treatment	1270	R	R	R
Date of most definitive surgical resection of the primary sit	e 3170	R		
Date of surgical procedure of primary site (CoC item: Date of first surgical procedure)	1200	R		R
Surgical procedure of primary site	1290	R	R	R
Surgical procedure of primary site at this facility	670	R		
Surgical margins of primary site	1320	R		0
Scope of regional lymph node surgery	1292	R	R	R
Scope of regional lymph node surgery at this facility	672	R		
Surgical procedure/other site	1294	R	R	R
Surgical procedure/other site at this facility	674	R		
Date of surgical discharge	3180	R		
Readmission to the same hospital within 30 days of surgic discharge	al 3190	R		
Reason for no surgery of primary site	1340	R	R	R
Date radiation started	1210	R		R
Location of radiation treatment	1550	R		
Radiation treatment volume	1540	R		
Regional radiation treatment modality	1570	R	R	R
Regional radiation dose: cGy	1510	R		
Boost radiation treatment modality	3200	R		

ITEM	NAACCR Item #	ACoS	NPCR	ISCR
Boost radiation dose: cGy	3210	R		
Number of treatments to this volume	1520	R		
Radiation/surgery sequence	1380	R	R	R
Date radiation ended	3220	R		
Reason for no radiation	1430	R		
Date systemic therapy started	3230	R		R
Date chemotherapy started	1220			R
Chemotherapy	1390	R	R	R
Chemotherapy at this facility	700	R		
RX SummSystemic/Sur Seq	1639	R	R	R
Date hormone therapy started	1230			R
Hormone therapy	1400	R	R	R
Hormone therapy at this facility	710	R		
Date immunotherapy started	1240			R
Immunotherapy	1410	R	R	R
Immunotherapy at this facility	720	R		
Hematologic transplant and endocrine procedures	3250	R	R	R
Date other treatment started	1250	R		R
Other treatment	1420	R	R	R
Other treatment at this facility	730	R		
Palliative care	3270	R		
Palliative care at this facility	3280	R		
OUTCOMES		1	I	
Date of first recurrence	1860	R		
Type of first recurrence	1880	R		
FOLLOW-UP			I	<u>I</u>
Date of last contact or death	1750	R	R	R
Vital status	1760	R	R	R
Cancer status	1770	R		R
Following registry	2440	R		
NPI – Following registry	2445	R		
Follow-up source (if available)	1790	R	R	R
Next follow-up source	1800	R		
Cause of death (Updated by Death Clearance procedures)	1910		R	R
Place of death (Updated by Death Clearance procedures)	1940		R	R
Remarks (text)	2680			0
Other primary tumors (text)				R
ADMINISTRATION		1	<u>I</u>	I.
Abstracted by	570	R		R
Facility ID number	540	R	R	R
(Required for participants in multiple-hospital registries)				
NPI-Reporting Facility	545	R	R	R

ITEM	NAACCR Item #	ACoS	NPCR	ISCR
Archive FIN	3100	R		
ICD revision number (for cause of death)	1920		R	R
Over-ride acsn/class/seq	1985	R		
Over-ride age/site/morph	1990	R	R	R
Over-ride CoC – site/type	1987	R		
Over-ride SeqNo/DxConf	2000		R	R
Over-ride Site/Lat/SeqNo	2010		R	R
Over-ride – site/type	2030	R	R	R
Over-ride histology	2040	R	R	R
Over-ride Report Source	2050		R	R
Over-ride III-define Site	2060		R	R
Over-ride leuk/lymphoma	2070	R	R	R
Over-ride site/behavior	2071	R	R	R
Over-ride site/lat/morph	2074	R	R	R
Over-ride hospseq/dxconf	1986	R		
Over-ride hospseq/site	1988	R		
Over-ride site/TNM-stggrp	1989	R		
Over-ride surg/dxconf	2020	R	R	R
Commission on Cancer coding system – current	2140	R		
Commission on Cancer coding system – original	2150	R		
Race coding system – current	170	R		
Race coding system – original	180	R		
Site coding system – current	450	R	R	R
Site coding system – original	460	R		
Morphology coding system – current	470	R	R	R
Morphology coding system – original	480	R		
ICD-O-2 conversion flag	1980	R		
ICD-O-3 conversion flag	2116	R	R	R
TNM edition number	1060	R		
RX coding system current	1460	R	R	R
Central tumor registry number - for State use only	20		R	R
Date case report received (stamp date) - for State use or	nly 2111		R	R
IHS Link (NPCR required if available) - for State use only	192		R	R
Follow-up Source Central - for State use only	1791		R	R
CS Version First (autocoded)	2935	R	R	R
CS Version Latest (autocoded)	2936	R	R	R

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# 1A. REPORTING FACILITY ID NUMBER

Item Length: 3
Data Type: Numeric
ACoS: Required
State Registry: Required

# Description

This is a required 3-character field for recording a unique 3-digit identification number assigned to each reporting facility in Indiana.

The Facility ID number identifies the facility reporting the case. It also allows the State Registry to collect information from multiple facilities that have seen the same patient for the same tumor. In the State Cancer Registry database, up to ten different facility ID numbers can be recorded for each tumor. Each of the ten facilities can be listed with its admission date, accession year and number, medical record number, and class of case for that tumor.

#### Instruction

Referring to Appendix D, enter your 3-digit facility ID number in this field.

## 1B. NPI-REPORTING FACILITY

Item Length: 10
Data Type: Numeric
ACoS: Required
State Registry: Required

Data item added for cases diagnosed 01/01/2007 or later, when available.

# Description

This is a required 10-character field that identifies the facility submitting the data in the record. NPI (National Provider Identifier) is a unique identification number for health care providers implemented by the Centers for Medicare & Medicaid Services as part of the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

#### Rationale

Each facility's NPI is unique. The number is essential to National Cancer Database (NCDB) for monitoring data submissions, ensuring the accuracy of data, and for identifying areas for special studies.

# Instructions

- a. NPI-Reporting Facility is automatically coded by the software provider.
- b. NPI should be recorded as available for cases diagnosed during 2007, and is required to be recorded for all cases diagnosed January 1, 2008.
- c. NPI may be blank for cases diagnosed on or before December 31, 2006.

## 2. ABSTRACTED BY

Item Length: 3
Data Type: Alphanumeric
Left Justified, Blank Fill
ACoS: Required

State Registry: Required

## Description

This is a required 3-character field to record the initials or assigned code of the individual who abstracted the case.

#### Rationale

This item is most useful for multi-staffed registries and can be used for quality control and management.

#### Instructions

- a. Record the initials or assigned code of the individual who abstracted this case. If the initials are less than three characters, left justify and blank fill.
- b. Do not code the data entry person <u>unless</u> that person is also the abstractor.

# **Instructions for RMCDS Facilities**

- a. The initials will automatically be entered in each abstract based on the identification used to log in.
- b. The initials automatically entered may be manually changed if a second abstracter completes a case in a session logged in by someone else.

## 3. TYPE OF REPORTING SOURCE

Item Length: 1
Data Type: Numeric

ACoS: N/A

State Registry: Required

Data item revised for cases diagnosed 01/01/2006 and later.

# **Description**

This is a required 1-character field for coding the source documents used to abstract the majority of information for the tumor being reported. The item is intended to indicate the completeness of information available to the abstractor.

#### Rationale

The code in this field can be used to explain why information for a tumor may be incomplete. For example, death certificate only cases have unknown values for many data items, so one may want exclude them from some analyses. The field also is used to minotor the success of non-hospital case reporting and follow-back mechanisms. All population-based registries should have some death certificate-only cases where no hospital admission was involved, but too high a percentage can imply both shortcomings in casefinding and that follow-back to uncover missed hospital reports was not complete.

Codes (effective for cases diagnosed 01/01/2006 and later)

- 1 Hospital inpatient; managed health plans with comprehensive, unified medical records
- 2 Radiation Treatment Centers or Medical Oncology Centers (hospital-affiliated or independent)
- 3 Laboratory only (hospital-affiliated or independent)
- 4 Physician's office/private medical practitioner (LMD)
- 5 Nursing/convalescent home/hospice
- 6 Autopsy only (diagnosed at autopsy)
- 7 Death certificate only
- 8 Other hospital outpatient units/surgery centers

# Notes:

- a. Code in the following priority order: 1, 2, 8, 4, 3, 5, 6, 7. This is a change to reflect the addition of codes 2 and 8 (for cases diagnosed 01/01/2006 and later) and to prioritize laboratory reports over nursing home reports. Facilities previously defined under code 1 have been split between codes 1, 2, and 8.
- b. Use the code that reflects the source documents used to abstract the majority of information for the tumor being reported. This may not be the source of original case finding. For example, if a case is identified through a pathology laboratory report review and all source documents used to abstract the case are from the physician's office, record code 4.

# **Definitions**

- a. Code 1 includes hospitals as well as specified managed health plans. Reports from health plans (e.g., Kaiser, Veterans Administration, military facilities), in which all diagnostic and treatment information is maintained centrally and available to the abstractor, are expected to be at least as complete as reports for hospital inpatients. Therefore, these sources are grouped with inpatients and given the code with the highest priority.
- b. Code 2 includes (radiation or medical) cancer treatment facilities, whether they are affiliated with a hospital or not. These sources usually have complete information on the cancer diagnosis, staging, and treatment.
- c. **Code 3** is generally for use by independent pathology laboratories. If a hospital's pathology department has a report on a non-hospital case (with no inpatient or outpatient record) and no other information is available, code 3 should be used. For example, a hospital that finds a reportable case by reviewing pathology reports should report the case as Reporting Source 3 if no other records or

information were available. This might happen if an outside physician contracted to use the hospital's pathology laboratory facilities.

- d. **Code 4** includes physician offices as well as independent, free-standing clinics with no hospital affiliation and that are not defined under Code 2. Examples of these may include surgery centers with no hospital affiliation and HMOs.
- e. **Codes 6 and 7** are used only when investigation can find no clinical diagnosis of any kind while the patient was alive.
- f. Code 8 sources would include, but would not be limited to, hospital outpatient surgery and nuclear medicine services. A physician's office that calls itself a surgery center should be coded as a physician's office. Surgery centers are equipped and staffed to perform surgical procedures under general anesthesia. If a physician's office calls itself a surgery center, but cannot perform surgical procedures under general anesthesia, code as a physician office.

SUSPENSE CASE

Item Length: 1
Data Type: Numeric
ACoS: N/A
State Registry: Optional

## Description

This is an optional 1-character field in the RMCDS abstract screen to record a code that identifies an incomplete record (suspense, premalignant). Records identified as incomplete will be bypassed when normal edits are applied. A suspense system can be created using this field by printing a suspense list of the incomplete cases.

The paper Hospital Abstract does not include this field, since the suspense system for paper abstractors is created by a separate filing of the abstracts or by using index cards.

Facilities using other vendors' registry programs should follow the applicable vendor's instructions for suspense cases.

#### Codes

- 1 Partial record (suspense, premalignant, incomplete)
- 0 Complete record

#### Instructions

- a. Record a 1 in the suspense field for cases that have not been completely abstracted.
- b. When the record is completely abstracted, change the code and apply edits to the record.
- c. Refer to Chapter 2, Section D for requirements related to suspense systems.

## 4. PATIENT LAST NAME

Item Length: 25
Data Type: Alphabetic
Left Justified, Blank Fill
ACoS: Required

State Registry: Required

# Description

This is a required 25-character field for the patient's last name. Left justify and leave unused space(s) at the right blank.

#### Instructions

a. In a hyphenated last name, record the hyphen (-) between the two surnames (last names). This might happen when a female marries and keeps her maiden name as part of her legal married name.

Example: SMITH-WALBRIDGE

b. Do not enter periods, apostrophes, blank spaces, punctuation, or other special characters (e.g., Jr, III) within the name.

Example 1: OHARA (NOT O'HARA)

Example 2: MCDONALD (NOT MC DONALD)

Example 3: STPIERRE (NOT ST. PIERRE OR SAINT PIERRE)

**Note:** The *FORDS* allows blanks, spaces, and apostrophes in the last name field. However, changing the name format at this point would compromise the linking or matching of new cases with cases previously entered in the registry. Therefore, it is advisable to continue following the old formatting rules.

c. Update the field if a patient marries and takes the spouse's last name. If a patient changes his/her legal name, enter the patient's most current legal name and put previous last name in the field for maiden name. If a patient has more than one tumor, previous records with different last names (AKA's) should be updated to show the most recent name change. The old name should be recorded in *Maiden Name*.

Example: Jane White, who had a primary in 1999, marries in 2000 and becomes Jane Black. In 2003 she has a second primary. Change the last name in the 1999 abstract from White to Black and record White in *Maiden Name*. Record the same names for the 2003 primary: Black (White in *Maiden Name*).

d. Do not leave the field blank. If the patient's last name is unknown, record UNKNOWN.

# 5. PATIENT FIRST NAME

Item Length: 14
Data Type: Alphabetic
Left Justified, Blank Fill
ACoS: Required
State Registry: Required

# Description

This is a required 14-character field for the patient's first name. Left justify and leave unused space(s) at the right blank.

# Instructions

- a. Record the patient's full first name.
- b. Truncate names longer than 14 characters.
- c. If the first name is not known, leave the field blank.

# 6. PATIENT MIDDLE NAME (MIDDLE INITIAL)

Item Length: 14
Data Type: Alphabetic
Left Justified, Blank Fill
ACoS: Required

State Registry: Required

# Description

This is a required 14-character field for the patient's middle name or middle initial. Left justify and leave unused space(s) at the right blank.

#### Instructions

- a. Record the patient's middle name or middle initial. If recording only a middle initial, do <u>not</u> enter a period after the letter.
- b. Truncate names longer than 14 characters.
- c. If the middle name is not known, leave the field blank.

# 7. PATIENT MAIDEN NAME

Item Length: 15 Data Type: Alphabetic Left Justified, Blank Fill

ACoS: N/A

State Registry: \*Required

\*Required if available for cases diagnosed 01/01/2006 and later.

# Description

This is an optional 15-character field for the maiden name of female patients who are married or who have been married. Left justify and leave unused space(s) at the right blank.

#### Instructions

- a. If a female is, or has been, married, record her maiden name.
- b. Truncate names longer than 15 characters.
- c. If the maiden name is not known or the patient does not have a maiden name, leave the field blank.
- d. Do not enter periods, apostrophes, blank spaces, punctuation, or other special characters (e.g., Jr, III) within the name.

Example 1: OHARA (NOT O'HARA)

Example 2: MCDONALD (NOT MC DONALD)

Example 3: STPIERRE (NOT ST. PIERRE OR SAINT PIERRE)

## 8. PATIENT ALIAS

Item Length: 15 Data Type: Alphabetic Left Justified, Blank Fill

ACoS: N/A

State Registry: \*Required

\*Required if available for cases diagnosed 01/01/2006 and later.

## Description

This is an optional 15-character field to record the alias, if the patient uses a different name or nickname. Left justify and leave unused space(s) at the right blank.

## Instructions

## a. First name only alias

If the patient uses an alias for a first name only, record the actual last name and the first name alias. In the RMCDS abstract screen, leave a blank space, without punctuation, between the last and first names.

Example: Ralph Williams uses the name Bud Williams. Record Williams Bud.

# b. Last name only alias

If the patient uses only a last name alias, record the last name alias and the actual first name. In the RMCDS abstract screen, leave a blank space, without punctuation, between the last and first names.

Example: Janice Smith uses the name Janice Brown. Record Brown Janice.

## c. Alias first and last name

If the patient uses an alias for the first and last name, record the last name alias and the first name alias. In the RMCDS abstract screen, leave a blank space, without punctuation, between the last and first names.

Example: Samuel Clemens uses the name Mark Twain. Record Twain Mark.

d. If the patient does not use an alias, leave the field blank.

## **GENERAL GUIDELINES FOR RECORDING PATIENT ADDRESS AT DIAGNOSIS**

#### Rationale

The address is a part of the patient's demographic data and has multiple uses. It will provide a referral pattern report and allow analysis of cancer clusters or environmental studies. Address at diagnosis may be corrected, but <u>never</u> changed or updated. Changing this field would destroy its usefulness.

#### Rules and Definitions: Use the following guidelines for all patient address data items.

- a. Record the patient's usual residence when the cancer was diagnosed. Normally a residence is the home named by the patient. Do not use a temporary address, such as a winter or vacation home. Legal status and citizenship are not factors in residency decisions. Rules of residency are identical to or comparable with rules used by the Census Bureau whenever possible. The registry can resolve residency questions by using the Census Bureau's definition: "The place where he or she lives and sleeps most of the time or the place the person considers to be his or her usual home." Vital statistics rules may differ from census rules. Do not record residence from the death certificate. Review each case carefully and apply the rules.
- b. Do not use current address. Record the address for the patient's home when he/she was diagnosed with cancer for both analytic cases (class of case 0, 1, or 2) and nonanalytic cases (class of case 3-7). If all or any part of the address is unknown, follow the instructions for unknowns under the applicable item heading in the following pages.
- c. Rules for persons without apparent residences:
  - (1) <u>Persons with More than One Residence</u> (summer and winter homes): Use the address the patient specifies if a usual residence is not apparent.
  - (2) <u>Persons with No Usual Residence</u> (transients, homeless): Use the address of the place they were staying when the cancer was diagnosed. This could be a shelter or the diagnosing facility.
  - (3) <u>Persons Away at School</u>: College students are residents of the school area. Boarding school children below college level are residents of their parents' home.
  - (4) <u>Persons in Institutions</u>: The Census Bureau states, "Persons under formally authorized, supervised care or custody" are residents of the institution. This includes:
    - Incarcerated persons
    - Persons in nursing, convalescent, and rest homes
    - Persons in homes, schools, hospitals, or wards for the physically disabled, mentally retarded, or mentally ill
    - Long-term residents of other hospitals, such as Veterans Administration (VA) or military hospitals
  - (5) <u>Persons in the Armed Forces and on Maritime Ships</u>: Members of the armed forces are residents of the installation area. Use the stated address for military personnel and their family. Military personnel may use the installation address or the surrounding community's address.

The Census Bureau has detailed residency rules for Naval personnel, Coast Guard, and maritime ships. Refer to Census Bureau publications for the detailed rules.

## Patient Address – Current

The State Registry does not collect the patient's current address, although there are separate fields in the RMCDS program for recording it. For further coding instructions on current address, refer to the *FORDS*, pages 15 and 49-54.

# 9. PATIENT ADDRESS (NUMBER AND STREET) AT DIAGNOSIS

Item Length: 40
Data Type: Alphanumeric
Left Justified, Blank Fill
ACOS: Required

State Registry: Required

# **Description**

This is a required 40-character field for the patient's house number and street address at the time of diagnosis. Enter the house number and street name or the rural mailing address. This may or may not be the patient's current address. If the patient has multiple tumors, the address may be different for each primary. See "General Guidelines for Recording Patient Address at Diagnosis" for detailed residency rules.

#### Rationale

The address is a part of the patient's demographic data and has multiple uses. It indicates referral patterns and allows for analysis of cancer clusters or environmental studies.

#### Instructions

- a. Record the number and street address of the patient's usual residence when the cancer was diagnosed.
- b. Avoid using punctuation, except when necessary to convey the meaning. Limit punctuation to periods when the period carries meaning (e.g., 39.2 RD), slashes for fractional addresses (e.g., 101 1/2 MAIN ST), and hyphens when the hyphen carries meaning (e.g., 289-01 MONTGOMERY AVE). Avoid using the pound sign (#) to designate address units whenever possible. If a pound sign is used, there must be a space between the pound sign and the secondary number.
- c. Do not update this data item if the patient's address changes.
- d. Use standard abbreviations recognized by the U.S. Postal Service (USPS). The USPS Postal Addressing Standards, Pub 28, November 2000 can be found on the Internet at <a href="http://pe.usps.gov/cpim/ftp/pubs/pub28/pub28.pdf">http://pe.usps.gov/cpim/ftp/pubs/pub28/pub28.pdf</a>. Standard abbreviations include, but are not limited to:

Apartment Avenue Boulevard Building Circle Court Department	APT AVE BLVD BLDG CIR CT DEPT	State Road Street Suite Terrace Unit	SR ST STE TER UNIT
Drive	DR		
Floor	FL	North	N
Lane	LN	Northeast	NE
Parkway	PKY	Northwest	NW
Place	PL	South	S
Post Office	PO	Southeast	SE
Road	RD	Southwest	SW
Room	RM	East	E
Rural Route	RR	West	W

Example 1: 123 MAIN ST APT 5 Example 2: RR 2 BOX 421

Example 3: 103 FIRST AVE SW APT 102

e. If the number and street address at diagnosis is not known, enter "UNKNOWN" in this field.

# 10. PATIENT ADDRESS (NUMBER AND STREET) AT DIAGNOSIS – SUPPLEMENTAL

Item Length: 40
Data Type: Alphanumeric
Left Justified, Blank Fill
ACOS: Required

State Registry: \*Required

\*Required if available for cases diagnosed 01/01/2006 and later.

## Description

This item provides the ability to store additional address information, such as the name of a place or facility (e.g., a nursing home or name of an apartment complex), at the time of diagnosis.

#### Rationale

A registry may receive the name of a facility instead of a proper street address containing the street number, name, direction, and other elements necessary to locate an address on a street file for the purpose of geocoding.

# **Instructions for Coding**

- a. Record the place or facility (e.g., a nursing home or name of an apartment complex) of the patient's usual residence when the tumor was diagnosed.
- b. If the patient has multiple tumors, the address may be different for subsequent primaries.
- c. Do not update this data item if the patient's address changes.
- d. If this address space is not needed, leave the item blank.

# 11. CITY/TOWN AT DIAGNOSIS

Item Length: 20
Data Type: Alphabetic
Left Justified, Blank Fill
ACoS: Required
State Registry: Required

# Description

This is a required 20-character field for the patient's usual city or town <u>at the time of diagnosis</u>. If the patient has multiple tumors, the address may be different for each primary. See "General Guidelines for Recording Patient Address at Diagnosis" for detailed residency rules.

## Rationale

The address is a part of the patient's demographic data and has multiple uses. It indicates referral patterns and allows for analysis of cancer clusters or environmental studies.

#### Instructions

- a. Record the city or town of the patient's usual residence when the cancer was diagnosed.
- b. Do not use punctuation or special characters and abbreviate when necessary.
- c. Do not update this data item if the patient's city/town of residence changes.
- d. If the city is not known, enter "UNKNOWN."

## 12. STATE AT DIAGNOSIS

Item Length: 2
Data Type: Alphabetic
ACoS: Required
State Registry: Required

Item revised for cases diagnosed 01/01/2007 and later.

## Description

This is a required 2-character field for the patient's usual state of residence at the time of diagnosis. See "General Guidelines for Recording Patient Address at Diagnosis" for detailed residency rules.

#### Rationale

The address is a part of the patient's demographic data and has multiple uses. It indicates referral patterns and allows for the analysis of cancer clusters or environmental studies.

#### Instructions

- a. Record the standard U.S. Postal Service 2-letter abbreviation for the state, territory, commonwealth, U.S. possession, or Canadian province/territory in which the patient resides at the time of diagnosis. The 2-letter codes appear on the following page.
- b. If the patient has multiple tumors, the state of residence may be different for each primary.
- c. Do not update this data item if the patient's state of residence changes.

# **Special Codes**

- CD Resident of Canada, NOS (province/territory unknown)
- US Resident of United States, NOS (state/commonwealth/territory/possession unknown)
- XX Resident of a country other than the U.S. (including its territories, commonwealths, or possessions) or Canada and the country is known. Code the country of residence in *County at Diagnosis*.
- YY Resident of a country other than the U.S. (including its territories, commonwealths, or possessions) or Canada and the country is unknown.
- ZZ Residence unknown

# **State Abbreviation Codes**

STATE	STATE			STATE	
Alabama	AL	Massachusetts	MA	Tennessee	TN
Alaska	AK	Michigan	MI	Texas	TX
Arizona	AZ	Minnesota	MN	Utah	UT
Arkansas	AR	Mississippi	MS	Vermont	VT
California	CA	Missouri	МО	Virginia	VA
Colorado	СО	Montana	MT	Washington	WA
Connecticut	СТ	Nebraska	NE	West Virginia	WV
Delaware	DE	Nevada	NV	Wisconsin	WI
District of Columbia	DC	New Hampshire	NH	Wyoming	WY
Florida	FL	New Jersey	NJ	OTHER	
Georgia	GA	New Mexico	NM	American Samoa	AS
Hawaii	HI	New York	NY	Guam	GU
Idaho	ID	North Carolina	NC	Puerto Rico	PR
Illinois	IL	North Dakota	ND	Virgin Islands	VI
Indiana	IN	Ohio	ОН	Palau	PW
Iowa	IA	Oklahoma	OK	Micronesia	FM
Kansas	KS	Oregon	OR	Marshall Islands	MH
Kentucky	KY	Pennsylvania	PA	Outlying Islands	UM
Louisiana	LA	Rhode Island	RI	APO/FPO Armed Services America	AA
Maine	ME	South Carolina	sc	APO/FPO Armed Services Europe	AE
Maryland	MD	South Dakota	SD	APO/FPO Armed Services Pacific	AP

# **Abbreviation Codes for Canadian Provinces and Territories**

PROVINCE		PROVINCE		
Alberta	AB	Nunavut	NU	
British Columbia	ВС	Ontario	ON	
Manitoba	MB	Prince Edward Island	PE	
New Brunswick	NB	Quebec	QC	
Newfoundland and Labrador	NL	Saskatchewan	SK	
Northwest Territories	NT	Yukon	YT	
Nova Scotia	NS			

# 13. POSTAL CODE (ZIP CODE) AT DIAGNOSIS

Item Length: 9
Data Type: Numeric
Left Justified, Blank Fill
ACoS: Required
State Registry: Required

# **Description**

This is a required 9-character field for the patient's postal (ZIP) code <u>at the time of diagnosis</u>. The 4-digit extension is optional. See "General Guidelines for Recording Patient Address at Diagnosis" for detailed residency rules.

## Rationale

The address is a part of the patient's demographic data and has multiple uses. It indicates referral patterns and allows for the analysis of cancer clusters or environmental studies.

#### Instructions

- a. For U.S. residents record the U.S. Postal Service ZIP code for the patient's residence <u>at the time of</u> diagnosis.
- b. The ZIP code field in the RMCDS program will accept the "ZIP plus 4" extended ZIP code. Do not enter a dash before the 4-digit extension.
  - Recording the 4-digit extension is optional. If the 4-digit extension is not recorded, left justify the 5-digit code and leave the remaining spaces blank.
- c. For residents of Canada and Puerto Rico record the postal code, left justify, and leave the remaining spaces blank.
- d. If the patient has multiple malignancies, the postal code may be different for each primary.
- e. Do not update this data item if the patient's postal code changes.

## **Special Codes**

88888 Permanent address in a country other than Canada, United States, or US possession <u>and</u> postal code is unknown.

99999 Permanent address in Canada, United States, or US possession and postal code is unknown.

## 14. COUNTY AT DIAGNOSIS

Item Length: 3
Data Type: Numeric
Right Justified, Blank Fill
ACoS: Required
State Registry: Required

# **Description**

This is a required 3-character field to record the county of the patient's usual residence <u>at the time of diagnosis</u>. See "General Guidelines for Recording Patient Address at Diagnosis" for detailed residency rules.

#### Rationale

This data item may be used for epidemiological purposes. It may be used, for example, to measure the cancer incidence in a particular geographic area.

#### Codes

Use the codes issued by the Bureau of Standards in the Federal Information Processing Standards (FIPS). FIPS codes for Indiana counties are listed on the following page.

#### Instructions

## a. Residents of Indiana

For Indiana Residents, enter the 3-digit FIPS code for the patient's county of residence at the time of diagnosis from the list on the following page.

# b. Residents of States Other than Indiana

- (1) If the patient is a resident of a state other than Indiana, and your facility does <u>not</u> collect identification codes for counties of that state, record the 998 code defined under "special codes."
- (2) If the patient is a resident of a state other than Indiana, <u>and</u> your facility collects identification codes for counties of that state, use the FIPS codes for that state. Appendix K lists the FIPS codes for counties in the states adjoining Indiana. If you need codes for states other than those provided, contact the State Registry.

# c. Residents of Countries other than the United States

- (1) If the patient is a resident of a country other than the United States, and your facility does <u>not</u> collect identification codes for other countries, record the 998 code defined under "special codes."
- (2) If the patient is a resident of a country other than the United States, <u>and</u> your facility collects identification codes for other countries, record the SEER Geocode for the country in this field. An XX code would have been recorded in *State at Diagnosis*.

For SEER Geocodes, see *The SEER Program Coding and Staging Manual*, First Edition (http://seer.cancer.gov/) or Standards for Cancer Registries Volume II: Data Standards and Data Dictionary Version 10.1, Eighth Edition, (http://www.naaccr. org).

d. Do not update this data item if the patient's county of residence changes.

# **Special Codes**

998 The patient resides outside of the state of the reporting facility.

999 Unknown county/country. The patient is a resident of Indiana but the address is unknown.

# **INDIANA COUNTY CODES**

FIPS	County	FIPS	County	FIPS	County
001	Adams Allen Bartholomew Benton Blackford	071	Jackson	141	St. Joseph
003		073	Jasper	143	Scott
005		075	Jay	145	Shelby
007		077	Jefferson	147	Spencer
009		079	Jennings	149	Starke
011	Boone	081	Johnson	151	Steuben
013	Brown	083	Knox	153	Sullivan
015	Carroll	085	Kosciusko	155	Switzerland
017	Cass	087	LaGrange	157	Tippecanoe
019	Clark	089	Lake	159	Tipton
021	Clay	091	LaPorte	161	Union
023	Clinton	093	Lawrence	163	Vanderburgh
025	Crawford	095	Madison	165	Vermillion
027	Daviess	097	Marion	167	Vigo
029	Dearborn	099	Marshall	169	Wabash
031	Decatur	101	Martin	171	Warren
033	DeKalb	103	Miami	173	Warrick
035	Delaware	105	Monroe	175	Washington
037	Dubois	107	Montgomery	177	Wayne
039	Elkhart	109	Morgan	179	Wells
041 043 045 047 049	Fayette Floyd Fountain Franklin Fulton	111 113 115 117 119	Newton Noble Ohio Orange Owen	181 183	White Whitley
051 053 055 057 059	Gibson Grant Greene Hamilton Hancock	121 123 125 127 129	Parke Perry Pike Porter Posey		
061 063 065 067 069	Harrison Hendricks Henry Howard Huntington	131 133 135 137 139	Pulaski Putnam Randolph Ripley Rush		

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**CENSUS TRACT 2000** 

Item Length: 6
Data Type: Numeric
Zero Fill

Zero Fill ACoS: N/A

State Registry: Required\*

\*Completed by the State Registry

# **Description**

This is a required 6-character field in the RMCDS abstract screen for recording a census tract code that identifies the patient's residence at time of diagnosis. The code pinpoints residence at diagnosis within a geographic area smaller than the county of residence. Census tract is collected to meet the requirements of the Federal cancer registries grant.

#### Rationale

Census tract codes allow central registries to calculate incidence rates for geographical areas having population estimates. This field allows a central registry to add Year 2000 Census tract to cases diagnosed in previous years.

#### Definition

Census tract codes originate from the Bureau of the Census and are constructed using the patient's address. The boundaries of census tracts are established cooperatively by local committees and the Census Bureau. The corresponding population of the census tract area can be obtained from the Census Bureau. Codes are available from state health departments or the Bureau of the Census.

#### Instructions

- a. The State Cancer Registry will code this item using computerized methods based on the patient's address at diagnosis. If your facility already collects census tract, please contact the State Registry to avoid unnecessary duplication of effort. The field is described here for general informational purposes.
- b. When coding census tract, the decimal point is assumed to be between the fourth and fifth positions of the field. Zeros are added to fill all six positions.
  - Example 1: Census tract 409.6 (0409.60) would be coded 040960. Example 2: Census tract 516.21 (0516.21) would be coded 051621.

## **Special Codes**

000000 Area is not census tracted

999999 Area is census tracted, but census tract is not available

blank Census Tract 2000 not coded

## **CENSUS TRACT CERTAINTY 2000**

Item Length: 1
Data Type: Numeric

ACoS: N/A

State Registry: Required

\*Completed by the State Registry

# **Description**

This is a required 1-character field in the RMCDS abstract screen for recording the basis of assignment of census tract for an individual record. This item is not coded by the hospital. The information is usually provided by a geocoding vendor service, but may be manually assigned by central registry staff. The codes are hierarchical, with lower numbers having priority.

#### Rationale

This item is helpful in identifying cases tracted from incomplete information or P.O. Box.

# Codes

- 1 Census tract based on complete and valid street address of residence
- 2 Census tract based on residence ZIP + 4
- 3 Census tract based on residence ZIP + 2
- 4 Census tract based on residence ZIP code only
- 5 Census tract based on ZIP code of P.O. Box
- 9 Unable to assign census tract or bloc numbering based on available information

blank Not applicable (e.g., census tracting not attempted); Census Tract Certainty information for 2000 not coded

# Instructions

<u>The State Cancer Registry will code this item</u> using computerized methods based on the patient's address at diagnosis. The field is described here for general informational purposes.

## 15. SOCIAL SECURITY NUMBER

Item Length: 9
Data Type: Numeric
ACoS: Required
State Registry: Required

# Description

This is a required 9-character field to record the patient's Social Security Number (SSN).

## Rationale

This item is extremely important in identifying, linking, and matching multiple records on the same patient and in differentiating patients with similar names at the State Cancer Registry. Every effort should be made to obtain the correct number for each patient.

#### Instructions

- a. Do not enter any dashes, other punctuation, or any alphabetical letters.
- b. <u>Do not record Social Security numbers that end with B or D.</u> These letters signify that the number is the spouse's and indicate that the patient is receiving benefits under the spouse's number. Code as 999999999.
- c. You can assume the Medicare number is the Social Security number if it is prefixed with "A" or "C." Do not enter the prefix "A" or "C" on the abstract as part of the Social Security number.

## **Special Codes**

99999999 The patient does not have a Social Security number or it is not available or unknown. Do not leave the field blank.

## 16. DATE OF BIRTH

Item Length: 8
Data Type: Numeric
ACoS: Required
State Registry: Required

# Description

This is a required 8-character field for recording the patient's birth date. The month is recorded in the first two spaces, the day in the third and fourth spaces, and the year in the last four spaces (MM-DD-YYYY). A zero must precede single-digit months and days.

#### Codes

	<u>Month</u>	<u>Day</u>	Year
01	January	01	Use four-digit year (e.g., 1952)
02	February	02	9999 Year unknown
03	March	03	
04	April		
05	May		
06	June	25	
07	July	26	
80	August		
09	September	30	
10	October	31	
11	November	99 Day unknown	1
12	December	-	
99	Month unknown		

Example: A birth date of April 21, 1952 would be entered on the form as 04/21/1952, and entered in the RMCDS program as 04211952.

## Instructions

If the month, day, or year is unknown, enter 9's in the appropriate spaces. Approximation is preferable to coding year unknown. When the exact birth year is unknown, an estimate should always be made.

## Examples:

- 1) The patient is 60 years old when admitted to the hospital on June 15, 2001 and no birth date is given. Record 99/99/1941.
- 2) Only 1941 is given as the year of birth. Record the patient's date of birth as 99/99/1941.
- 3) You know the patient was born in June 1941 but the exact date is unknown. Record 06/99/1941.
- 4) The birth date, birth year, or patient's age cannot be estimated or is unknown. Record 99/99/9999.

# AGE AT DIAGNOSIS Item Length: 3 Data Type: Numeric Right Justified, Zero Fill ACoS: Required State Registry: Optional

# Description

This is an optional 3-character field in the RMCDS abstract screen for recording patient age at the time of diagnosis. The patient's age at diagnosis is automatically calculated by the RMCDS program after the date of birth and date of diagnosis are recorded.

### **Definition**

"Age at Diagnosis" is the patient's age at his or her last birthday before diagnosis.

# Examples:

000 Less than one year old

001 One year old, but less than two years old

002 Two years old

... Actual age in years

999 Unknown age

# **Instructions for Facilities Using RMCDS**

- a. If the date of birth and date of diagnosis are recorded, leave the item blank. The RMCDS software program will automatically calculate age.
- b. If either the date of birth or the date of diagnosis is unknown, you may manually enter the age at diagnosis in the RMCDS program if you know or can estimate the patient's age, even without a birth date or diagnosis date.

### 17. PLACE OF BIRTH

Item Length: 3 ACoS: Required

State Registry: Required if available

# Description

This is a 3-character field in the RMCDS abstract screen for recording a numeric code that identifies the state or country (if outside the United States) of the patient's birth. The State Registry requires the item if the information is available.

#### Codes

Use SEER Geocodes for *Place of Birth*. See *The SEER Program Coding and Staging Manual*, First Edition (http://seer.cancer.gov/) or Standards for Cancer Registries Volume II: Data Standards and Data Dictionary Version 10.1, Eighth Edition, (http://www.naaccr. org).

# **Special Codes**

000 United States, NOS

998 Place of birth outside of the United States, no other detail known

999 Place of birth unknown

### Instructions

For further coding instructions, refer to the FORDS, page 56.

#### 18. **MEDICAL RECORD NUMBER**

Item Length: 11 Data Type: Alphanumeric Right Justified, Blank Fill ACoS: Required

State Registry: Required

# Description

This is a required 11-character field to record the patient's medical record number. The medical record number is a patient identification number usually assigned by a hospital's medical record or health information management (HIM) department.

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	If the number is less than 11 digits, right justify and leave the leading spaces blank.
a.	if the number is less than 11 digits, right justify and leave the leading spaces blank.
	Example: Medical record number 24937 should be entered as 24937.
	<b>Note</b> (for facilities using RMCDS): The medical record number may be entered from the left (left justified). After the record is exited, the RMCDS program will automatically right justify the number.

- b. Do not include any hyphens, dashes, slashes, or other punctuation.
- c. If the hospital uses the patient's Social Security Number for the medical record number, record it in this field without dashes or spaces. Right justify and leave the leading spaces blank.

#### **Special Codes** \_\_\_\_UNK The patient's medical record number is unknown. Radiation therapy department patient without HIM medical record number \_\_\_\_RT \_\_\_\_SU One-day surgery clinic patient without HIM medical record number The patient does not have a medical record number at your hospital. blank

Note: Other standard abbreviations may be used to indicate departments within the facility for patients without HIM numbers.

19. SEX

Item Length: 1
Data Type: Numeric
ACoS: Required
State Registry: Required

# **Description**

This is a required 1-character field to record a code that identifies the patient's sex.

### Rationale

This data item is used to compare cancer rates and outcomes by site. The same sex code should appear in each medical record for a patient with multiple tumors.

# Codes

- 1 Male
- 2 Female
- 3 Other (hermaphrodite)
- 4 Transsexual
- 9 Not stated

# PRIMARY PAYER AT DIAGNOSIS

Item Length: 2 Data Type: Numeric ACoS: Required

State Registry: Required if available\*

\*Required if available for cases diagnosed 01/01/2006 and later.

# Description

This is a required 2-character field to identify the patient's primary payer/insurance carrier at the time of initial diagnosis and/or treatment.

### Rationale

This item is used in financial analysis and as an indicator for quality and outcome analyses. Joint Commission of Accreditation of Healthcare Organizations (JCAHO) requires the patient admission page to document the type of insurance or payment structure that will cover the patient while being cared for at the hospital.

# Codes

Code	Label	Definition
01	Not insured	Patient has no insurance and is declared a charity write-off.
02	Not insured, self-pay	Patient has no insurance and is declared responsible for charges.
10	Insurance, NOS	Type of insurance unknown or other than the types described in the definitions for codes 20, 21, 31, 35, 60-68.
20	Private Insurance: Managed care, HMO, PPO	An organized system of prepaid care for a group of enrollees usually within a defined geographic area. Generally formed as one of four types: a group model, an independent physician association (IPA), a network, or a staff model. "Gate-keeper model" is another term for describing this type of insurance.
21	Private Insurance: Fee-for-Service	An insurance plan that does not have negotiated fee structure with the participating hospital. Type of insurance plan not coded as 20.
31	Medicaid	State government administered insurance for persons who are uninsured, below the poverty level, or covered under entitlement programs.
		Medicaid other than those described in the definition for code 35.
35	Medicaid - Administered through a Managed Care plan	Patient is enrolled in Medicaid through a Managed Care program (e.g., HMO or PPO). The managed care plan pays for all incurred costs.
60	Medicare without supplement, Medicare, NOS	Federal government funded insurance for persons who are 62 years of age or older, or are chronically disabled (social security insurance eligible). Not described in the definitions for codes 61, 62, or 63.
61	Medicare with supplement, NOS	Patient has Medicare and another type of unspecified insurance to pay costs not covered by Medicare.
62	Medicare - Administered through a Managed Care plan	Patient is enrolled in Medicare through a Managed Care plan (e.g., HMO or PPO). The Managed Care plan pays for all incurred costs.
63	Medicare with private supplement	Patient has Medicare and private insurance to pay costs not covered by Medicare.
64	Medicare with Medicaid eligibility	Federal government Medicare insurance with State Medicaid administered supplement.

Code	Label	Definition
65	TRICARE	Department of Defense program providing supplementary civilian-sector hospital and medical services beyond a military treatment facility to military dependents, retirees, and their dependents.
		Formerly CHAMPUS (Civilian Health and Medical Program of the Uniformed Services).
66	Military	Military personnel or their dependents who are treated at a military facility.
67	Veterans Affairs	Veterans who are treated in Veterans Affairs facilities.
68	Indian/Public Health Service	Patient who receives care at an Indian Health Service facility or at another facility and the medical costs are reimbursed by the Indian Health Service.
		Patient receives care at a Public Health Service facility or at another facility and medical costs are reimbursed by the Public Health Service.
99	Insurance status unknown	It is unknown from the patient's medical record whether or not the patient is insured.

#### Instructions

- a. Record the applicable code from the above list for the type of insurance reported on the patient's admission page.
- b. Codes 21 and 65-68 are to be used for patients diagnosed on or after January 1, 2006.
- c. If more than one payer or insurance carrier is listed on the patient's admission page, record the first.
- d. If the patient's payer or insurance carrier changes, do not change the initially recorded code.

# Codes with Examples:

- 01 An indigent patient is admitted with no insurance coverage.
- 20 A patient is admitted for treatment and the patient admission page states the primary insurance carrier is an HMO.
- 62 A 65-year old male patient is admitted for treatment and the patient admission page states the patient is covered by Medicare with additional insurance coverage from a PPO.

# 20. RACE AND SPANISH ORIGIN (RACE AND ETHNICITY)

Item Length: 2 + 1
Data Type: Numeric
ACoS: Required
State Registry: Required

#### Description

This is a required 2-character field to record a code that identifies the patient's race and a required 1-character field to record a code for the patient's origin, if of Spanish/Hispanic descent.

#### **Codes for Race**

- 01 White
- 02 Black
- 03 American Indian, Aleutian, or Eskimo
- 04 Chinese
- 05 Japanese
- 06 Filipino
- 07 Hawaiian
- 08 Korean
- 09 Asian Indian, Pakistani
- 10 Vietnamese
- 11 Laotian
- 12 Hmong
- 13 Kampuchean (including Khmer and Cambodian)
- 14 Thai
- 20 Micronesian, NOS
- 21 Chamorran
- 22 Guamanian, NOS
- 25 Polynesian, NOS
- 26 Tahitian
- 27 Samoan
- 28 Tongan
- 30 Melanesian, NOS
- 31 Fiji Islander
- 32 New Guinean
- 88 No further race documented (for Race 2-5 in cases diagnosed 01/01/2000 and later)
- 96 Other Asian, including Asian, NOS and Oriental, NOS
- 97 Pacific Islander, NOS
- 98 Other
- 99 Unknown

Codes 20-97 were adopted for use effective with 1991 diagnoses. Code 14 was adopted for use effective with 1994 and later cases.

# **Definitions**

- a. Code 01 (white) includes Mexican, Puerto Rican, Cuban, and all other Caucasians.
- Code 02 (black) includes persons reported as African American, Afro-American, Negro, brown, or colored.
- c. Code 13 (Kampuchean) includes patients whose race is listed as Cambodian.

#### Instructions

- a. Additional races reported by the person should be coded in *Race 2*, *Race 3*, *Race 4*, and *Race 5*. If the patient is multiracial, code all races using *Race 2* through *Race 5*,and code all remaining *Race* items 88.
- b. All tumors for the same patient should have the same race code.

- c. If Race 1 is coded 99, then Race 2 through Race 5 must all be coded 99. If Race 2, 3, or 4 is coded 88 or 99, then all the subsequent Race items must be coded with the same value.
- d. For cases diagnosed prior to January 1, 2000 (Race Coding System-Current is less than six), Race 2 through Race 5 must be blank unless the patient has more than one primary with at least one primary diagnosed after January 1, 2000. In this case, the race codes for all primaries must be the same as the one for the primary diagnosed after January 1, 2000. Race Coding System –Current must be six and data items Race 2 through Race 5 that do not have specific race recorded must be coded 88.
- e. Race 1 is the field used to compare with race data on cases diagnosed prior to January 1, 2000.
- f. Race is based on birth place information when place of birth is reported as China, Japan, or the Philippines and race is reported only as Asian, Oriental, Mongolian, or Yellow.

If place of birth is China, Japan, or the Philippines, and race is <u>not</u> reported, code the race as 99 (Unknown). Place of birth alone can not be used to determine race or ethnicity.

# Codes with Examples:

- 01 A patient was born in Mexico of Mexican parentage. Code also Spanish/Hispanic Origin.
- 02 A black female patient. A specific race code (other than blank or 99) must not occur more than once. For example, do not code "Black" in *Race 1* for one parent and "Black" in *Race 2* for the other parent.
- 05 A patient has a Japanese father and a Caucasian mother. (Caucasian will be coded in *Race 2*). If a person's race is recorded as a combination of white and any other race, code to the other race in the *Race 1* field and then code Caucasian as "White" in the next race field.
- 05 A patient's race is listed as Asian and the birthplace is Japan. Code to birthplace. When the race is recorded as "Oriental," "Mongolian," or "Asian," and the place of birth is recorded as China, Japan, the Philippines, or another Asian nation, code the race based on birthplace information.
- 07 A patient has a Hawaiian father, black mother, Japanese grandfather, and Korean grandmother. If a person's race is recorded as a combination of Hawaiian and any other race(s), code the person's primary race as Hawaiian and code the other races in *Race 2*, *Race 3*, *Race 4*, *and Race 5* as appropriate. In this case, black to *Race 2*; Japanese to *Race 3*; and Korean *to Race 4*.
- 08 A patient is of Korean and Asian ancestry. Do not code "Asian" in a subsequent race field if a specific Asian race(s) has already been coded.
- 25 A patient with a Polynesian mother, Tahitian father, and Samoan grandparents.
- 99 A patient's race is unknown. Race 2 through Race 5 must also be 99.

# **Description for Spanish Origin**

This item identifies persons of Spanish/Hispanic surname or ethnicity. Persons of Spanish/Hispanic origin may be of any race, but these categories are generally not used for native Americans, Filipinos, or others who may have Spanish surnames.

#### **Codes for Spanish Origin**

- 0 Non-Spanish; non-Hispanic; not Spanish surname
- 1 Mexican (includes Chicano)
- 2 Puerto Rican
- 3 Cuban
- 4 South or Central American (except Brazilian)
- 5 Other specified Spanish/Hispanic origin (includes European and third or fourth generation patients coded 1, 2, 3, or 4)

- Spanish, NOS; Hispanic, NOS; Latino, NOS (There is evidence other than surname or maiden name that the person is Hispanic, but he/she cannot be assigned to any of the categories 1 to 5; Spanish/Hispanic surname but country of origin unknown.)
- 7 Spanish surname only (The only evidence of the person's Hispanic origin is surname or maiden name and there is no contrary evidence that the person is not Hispanic.)
- 9 Unknown whether Spanish or not

Code 7 was adopted for use effective with 1994 diagnoses. It does not include computer assignment of ethnicity.

# **Definitions and Rules for Spanish Origin**

- a. Use code 0 (Non-Spanish; non-Hispanic) for Portuguese and Brazilian persons.
- b. Code European Spanish and Basque as other specified Spanish/Hispanic origin (Code 5).
- c. Follow the rules for race in coding patients with mixed parentage.
- d. If the patient has multiple tumors, all records should have the same code.

# 21. USUAL OCCUPATION

Item Length: 40 Data Type: Text ACoS: N/A

State Registry: Required

# Description

This is a required text field to record the patient's occupation, if available. This data item applies only to patients who are 14 years or older at the time of diagnosis.

#### Rationale

Occupation is collected to meet the requirements of the Federal cancer registries grant. The item may be used to identify new work-related health hazards and to identify occupational groups in which cancer screening or prevention activities may be beneficial. It may also serve as an additional measure of socioeconomic status.

#### Instructions

- a. Record the patient's usual occupation (that is, the kind of work performed during most of the patient's working life before diagnosis of this tumor). This may be different from the occupation at the time of diagnosis. <u>Do not record "retired."</u>
- b. If usual occupation is not available or is unknown, record the patient's current or most recent occupation or any known occupation.
- c. If the patient was a housewife/househusband and <u>also</u> worked outside the home during most of his/her adult life, record usual occupation outside the home.
  - If the patient was a housewife/househusband and did <u>not</u> work outside the home for most of his/her adult life, record "housewife" or "househusband."
- d. If the patient was not a student or housewife and had never worked, record "never worked" as the usual occupation.
- e. If the patient is less than 14 years of age at the time of diagnosis, leave the field blank.
- f. If no information related to the patient's occupation is available, record "UNKNOWN."
- g. Update this field if better information is obtained as to the usual occupation of the patient.

**Note:** The *Occupation Code* field that follows *Usual Occupation* in the RMCDS screen abstract is for the Census Bureau occupation codes. Reporting facilities should leave the field blank. The codes will be assigned at the State Registry.

### 22. USUAL INDUSTRY

Item Length: 40 Data Type: Text ACoS: N/A

State Registry: Required

# Description

This is a required text field to record the company or industry, if available, for the occupation recorded in the preceding field. This data item applies only to patients who are 14 years or older at the time of diagnosis.

#### Rationale

Both occupation and business/industry are required to accurately describe an individual's occupation. The item may be used to identify new work-related health hazards and to identify worksite-related groups in which cancer screening or prevention activities may be beneficial. It may also serve as an additional measure of socioeconomic status.

#### Instructions

- a. Record the primary type of activity carried on by the business/industry where the patient was employed for the most number of years before diagnosis of this tumor. This may be different from the company or industry of the patient's occupation at the time of diagnosis.
- b. Be sure to distinguish among "manufacturing," "wholesale," "retail," and "service" components of an industry that performs more than one of these components.
- c. If the primary activity carried on at the location where the patient worked is unknown, it may be sufficient to record the name of the company (with city or town) for which the patient performed his/her usual occupation.
- d. If current or most recent occupation, rather than usual occupation is recorded, record the patient's current or most recent business/industry.
- e. Update this field if better information is obtained as to the usual industry of the patient.
- f. There should be an entry for Usual Industry if any occupation is reported. If no information is available regarding the industry in which the reported occupation was carried out, record "UNKNOWN."
- g. If the patient is less than 14 years of age at the time of diagnosis, leave the field blank.
- h. Examples of occupation/industry include: Sales clerk/department store; auto mechanic/auto dealer.

**Note:** The *Industry Code* field that follows *Usual Industry* in the RMCDS screen abstract is for the Census Bureau industry codes. Reporting facilities should leave the field blank. The codes will be assigned at the State Registry.

ACoS: N/A

State Registry: Optional

**CONTACT INFORMATION** 

NAME-SPOUSE/PARENT

**FOLLOW-UP CONTACT-NAME** 

FOLLOW-UP CONTACT PHONE NUMBER

**FOLLOW-UP CONTACT RELATION** 

FOLLOW-UP CONTACT-NO + STREET

**FOLLOW-UP CONTACT SUPPL** 

**FOLLOW-UP CONTACT-CITY** 

**FOLLOW-UP CONTACT-STATE** 

**FOLLOW-UP CONTACT-POSTAL** 

**Description** The fields listed above are optional fields in the RMCDS abstract screen for items that may be useful in follow-up procedures. Facilities that do not collect these items may leave the fields blank. The State Registry does not collect the items.

# 23. OTHER PRIMARY TUMOR(S)

Data Type: Text ACoS: N/A

State Registry: Required

# Description

This is a required text field in the paper and RMCDS abstracts for recording any other primary, malignant tumors from the patient's history, or other primary tumors diagnosed simultaneously with or after the tumor being reported. Facilities using other types of registry software should follow their vendor's instructions for recording text about other primary tumors.

#### Rationale

Text is needed to justify the codes selected for the data items and to record information that is not coded at all. The text is used for quality control and special studies.

### Instructions

a. Record site, histology, date of diagnosis, and sequence number for all other primary, malignant tumors from the patient's history, or other primary tumors diagnosed simultaneously with or after the tumor being reported.

Example: Right breast, infiltrating duct carcinoma, July 1980, 01

- b. Follow ACoS rules for multiple and single primaries as defined in this chapter under Item 27, Sequence on page 76; Item 33, *Primary Site* on pages 87-92; Item 36a, *Histology* on pages 99-104; and in Appendix F on pages 315-317.
- c. If the person does not have, or has not had, another primary, malignant tumor, record "None."

# 24. DATE OF FIRST CONTACT (INPATIENT OR OUTPATIENT ADMISSION DATE)

Item Length: 8
Data Type: Numeric
ACoS: Required

State Registry: Required

# **Description**

This is a required 8-character field for the date the patient was first seen at or first admitted to your hospital for this tumor after your reference date. Use whichever date is earlier. The month is entered in the first two spaces, the day in the third and fourth spaces, and the year in the last four spaces (MM-DD-YYYY). A zero must precede single-digit months and days.

#### Codes

	<u>Month</u>	<u>Day</u>	<u>Year</u>
01 02	January February	01 02	Use four-digit year (e.g., 2002) 9999 Year unknown
03	March	03	
04	April		
05	May	•••	
06	June	25	
07	July	26	
80	August		
09	September	30	
10	October	31	
11	November	99 Day unknowi	n
12	December		
99	Month unknown		

#### Instructions

- a. Record the first (earliest) date the patient was seen at your hospital for this tumor <u>following your hospital's reference (starting) date</u> for the registry. Record the earliest date the patient was seen with either evidence of cancer or for treatment of cancer, regardless of whether it was as an inpatient or outpatient.
- b. If the patient was first seen as an <u>inpatient</u>, record the date the patient was <u>first</u> admitted to your hospital for this primary tumor. Ignore subsequent readmission dates for this same tumor.
- c. If the patient was first seen as an <u>outpatient</u>, enter the date the patient was <u>first</u> seen in the outpatient department for this primary tumor. For cases diagnosed by scans or x-rays on an outpatient basis <u>at your hospital</u> and then admitted to your hospital, record the date of the scan or x-ray. If patient returned for subsequent outpatient visits, use only the initial date.

Example:

A patient has an outpatient mammography that is suspicious for malignancy on February 12, 2003 and subsequently is admitted for an excisional biopsy or radical surgical procedure on February 14, 2003. Record the date of the mammography (February 12, 2003) as the date of first contact/first admission to this facility.

- d. For cases diagnosed in the staff physician's office and then referred to your hospital for <u>first</u> course of therapy, record the date the patient was first seen at your hospital as an inpatient or outpatient.
- e. For cases diagnosed at another hospital, the date of first contact would be the date first seen at your hospital for treatment of this tumor, even if the patient was previously seen at your hospital as a consultation or for other reasons and no treatment was given for cancer.
- f. If the primary was diagnosed during a <u>long-term hospitalization</u> (those in nursing homes, psychiatric facilities, or VA hospitals), use the date of diagnosis as the date of first contact.

Example:

A patient has been an inpatient for several months at a Veterans Administration Hospital for an unrelated illness. After having been hospitalized for several months a new primary is discovered during a routine exam. Enter the date the diagnosis was made, rather than the date the patient was first admitted to the VA Hospital.

- g. If the cancer was not suspected while the patient was alive and hospitalized, but was an incidental finding on post mortem exam (<u>autopsy</u>), use the date of death as the date of first contact. There must be no suspicion of cancer prior to autopsy.
- h. For cases diagnosed at your hospital <u>prior</u> to your reference (starting) date (class of case 4), record the first date seen for that malignancy <u>after</u> your reference date.

Example:

A patient was diagnosed at your hospital December 20, 1985. Your reference date is January 1, 1987. The patient was readmitted to your hospital January 5, 1995 for a recurrence of the initial primary. The date of first contact would be January 5, 1995. The date of diagnosis would still be December 20, 1985.

i. For pathology-only cases (Class of Case 7), record the date on which the specimen was collected.

#### **Special Code**

00000000 Patient was never seen or treated in the hospital. Use for class of case 6 (diagnosed and all of the first course of treatment only in a staff physician's office).

<u>Coding Tip</u>: The year in the Date of First Contact item should match the first four digits of your hospital accession number (Item 26) for most patients' first primary (unless patient was admitted at the end of one year and not diagnosed until the next year).

# 25. ACCESSION YEAR THIS PRIMARY (YEAR FIRST SEEN FOR THIS PRIMARY)

Item Length: 4
Data Type: Numeric

ACoS: N/A

State Registry: Required

# Description

This is a required 4-character field to record the year the patient was first seen at your hospital for diagnosis and/or treatment of <u>this</u> primary. The accession year for this primary relates only to one primary tumor. A patient with multiple primaries can have a different year in this field for each primary.

#### Rationale

Hospital registries can produce an accession register using this data item. The accession register identifies all primaries first treated or seen at your hospital for a given year. The accession year this primary may differ from the first four digits of the accession number, since the accession year this primary is case-/tumor-specific, rather than patient-specific. It also may differ from the diagnosis year, since it relates to the specific facility, and not to the tumor.

#### Instructions

- a. Record the first year the patient was seen at your hospital for diagnosis and/or treatment of this primary after your reference date.
  - Example 1: A patient had surgery for rectal carcinoma at another hospital in December 2002 and started radiation therapy at your hospital in January 2003. Assign 2003 as the accession year this primary.
  - Example 2: A breast cancer patient had initial therapy at another hospital in July 2002. The patient enters your hospital in April 2003 for treatment of recurrent breast cancer. Assign 2003 as the accession year this primary.
  - Example 3: Your reference date is January 1, 1997. A patient entered your hospital with cancer of the larynx in July 1996. The patient returns to your hospital in August 2000 with recurrent laryngeal cancer. Assign 2000 as the accession year this primary.
- b. Accession year this primary will match the first four digits of the patient's accession number for the first primary only. For subsequent primaries diagnosed and/or treated in a later year, the accession year this primary will be a different year than the first four digits of the patient's accession number.
  - Example: A patient has a breast primary in 2001 and is assigned an accession number 200100150. The accession year this primary was recorded as 2001. The patient developed a second primary of the right kidney in 2003. Assign 2003 as the accession year this primary for the kidney primary, even though the first four digits of his accession number are 2001.
- c. Patients seen at your hospital at the end of the year may present unusual problems. A patient may have inconclusive scans or tests in December and not be diagnosed until January. Use the year of diagnosis as the accession year this primary.
  - Example: A patient is admitted to your hospital in December 2002 and diagnosed in January 2003. Assign 2003 as the accession year this primary.

# 26. HOSPITAL ACCESSION NUMBER

Item Length: 9
Data Type: Numeric
ACoS: Required
State Registry: Required

# Description

This is a required 9-character field for the unique number assigned to each cancer patient seen at your hospital. The first 4 digits indicate a year (YYYY) and the next 5 digits indicate a sequential number (#####) in which the cancer was first entered into the registry, so that the accession number is recorded as YYYY#####. Each new calendar year starts over again on January 1 with accession number 00001.

Examples: 200200007; 200200014; 200200123; 200200537; 200300001.

#### Instructions

- a. Assign accession numbers on a sequential basis, with the first four digits indicating the year the patient was first seen at your facility for the diagnosis and/or treatment of cancer. The last five digits indicate the numerical order in which the registry entered the case for that calendar year.
- b. The first four digits of the accession number are based on the date the patient was first seen for the diagnosis and/or treatment of cancer at your hospital following your registry's reference date. The "reference date," which always begins on January 1 of a given year, is the date the hospital first started their registry. Therefore, the first four digits of the accession number is never less than the registry's reference date unless the reference date is changed (see Exception below).
  - Example: If you began reporting cancer cases to the State Cancer Registry when the requirement began on January 1, 1987 and continue to report only for state requirements, your reference date would be January 1, 1987. All cases in your registry should have an accession number of 1987\_\_\_\_ or higher.
  - **Exception:** If a patient is first accessioned into the registry, then the registry later changes its reference date and the patient is subsequently accessioned into the registry with a new primary, use the original accession number associated with the patient and code the sequence appropriately.
  - Example: A patient is diagnosed by the hospital with prostate cancer in 1991 and assigned accession number 199100067. The registry later sets a new reference date of January 1, 1997. The same patient is admitted and diagnosed with lymphoma in 2005. Use accession number 199100067 and sequence 02 for the lymphoma case.
- c. Enter leading zeros for numbers less than five digits.
  - Example: A patient is first admitted to your facility for treatment of cancer in 2003. The first four digits of the accession number are 2003. If the patient is the 25<sup>th</sup> patient to be accessioned (entered) in your registry in 2003, the last five digits of the accession number would be 00025. The full accession number for this patient would be 200300025.
- d. Assign a unique accession number to each patient. A patient cannot have more than one accession number at your facility. Patients who contract a second or third primary cancer retain the same 9-digit accession number for primaries. (The sequence number will distinguish between the various primaries.)

Before assigning an accession number to a patient, check your alphabetic index to see if the patient has ever been entered in your registry before. Do <u>not</u> assign a new accession number to a patient who already has another accession number.

Example: John Smith was first seen and diagnosed at your hospital in 1999 with a primary cancer of the prostate. He was assigned accession number 199900010-00 (1999 is the year first accessioned, 00010 is the accession number, and 00 is the sequence number). In 2003, he was diagnosed with a second primary cancer of the pancreas. The accession number for the pancreatic primary would be 199900010-02. The patient will always keep his originally assigned accession number. Only the sequence number changes. The sequence number will distinguish the two primaries.

- e. Each new patient added to the registry should be given the next highest number in sequential order (200300001, 200300002, 200300003, etc.). The order patients are assigned an accession number within a particular year does not matter. Accession numbers do not need to be kept in date order of diagnosis, admission, discharge, or abstracting. For example, a case first seen in September 2002 (200200175) can have a lower accession number than a case first seen in July 2002 (200200176).
- f. <u>Do not skip over numbers to allow for earlier cases to be inserted later</u>. Numeric gaps in accession numbers should occur only if a case is deleted from your database. Do not reuse the accession number for a different patient to avoid any chance of two cases having the same accession number.
- g. The first four digits of the accession number are the year in which the patient was first seen at <u>your</u> hospital. If the patient's first primary was seen at another hospital and therefore was not recorded in your registry, enter the year the patient's earliest sequenced primary was diagnosed and/or treated at <u>your</u> facility.
  - Example 1: Mary Jones was diagnosed with her first primary malignancy at Hospital A in 2001. Hospital A gave her accession number 200100021-00, since she was the 21<sup>st</sup> patient to be accessioned at Hospital A in 2001. In 2003, Mary Jones went to Hospital B with a second primary. Hospital B assigned her accession number 200300152-02 since she was seen at hospital B for the first time in 2003 and was the 152<sup>nd</sup> patient entered in their registry. Hospital A should change their sequence number from 200100021-00 to 200100021-01.
  - Example 2: A new primary for a patient initially diagnosed and admitted in 2001 was not identified by the tumor registrar until 2003. The first four digits of the accession number would be 2001, based on the date of admission (date of first contact for this primary). It would not be 2003, the year the primary was identified by the registrar.
- h. Class of Case 0, 1, and 6: The first four digits of the accession number are the year the patient was first seen at your hospital or in a staff physician's office for diagnosis <u>following your reference date</u>. (Class of case is explained in Item 28 in this chapter).

The first four digits of the accession number match the year recorded in Date of First Contact for the first accessioned primary (Item 24, explained earlier in this chapter).

- Example 1: A patient who was first seen as an outpatient in 2003 is the first patient to be entered into your registry in 2003. His accession number would be 200300001.
- **Exception:** If the patient was first seen at your facility at the end of one year but was not diagnosed until the beginning of the next year, his accession number should be the year he was diagnosed.
- Example 2: A patient first entered your hospital as an inpatient in December 2002, but was not diagnosed until January 2003. The first four digits of the accession number should be 2003, since the majority of the reports and service for this cancer would be provided in 2003.

- i. Class of Case 2 and 3: The first four digits of the accession number are the year the patient was first seen at your hospital for treatment after your reference date, whether as an inpatient or outpatient admission.
  - Example 1: A patient had cancer-directed surgery at another hospital in December 2002. Your facility initiated outpatient radiation therapy January 2003. Your accession number for this patient is 2003\_\_\_\_.
  - Example 2: A patient had initial treatment in another facility in 2001. The patient is admitted and treated at your hospital in November 2002 for recurrent cancer. Your accession number is 2002\_\_\_\_\_.
  - Example 3: The patient's first primary was initially diagnosed in 1985. The patient was admitted for a second primary in 2003. The hospital's reference date is January 1, 1987. The first four digits of the accession number on the second primary would be 2003, since that is the year the patient was first seen following the registry's reference date. The first primary diagnosed in 1985 would not be accessioned or abstracted. The second primary diagnosed in 2003 would have a sequence number of 02, even though there will be no abstract for sequence 01.
- j. Class of Case 4: The first four digits of the accession number are the first year in which your hospital saw the patient for the management and/or treatment of active cancer after your reference date.
  - Example: Your reference date is January 1, 1987. Your facility treated a patient for cancer of the larynx in 1985. The patient returns in March 2001 for treatment of recurrent laryngeal cancer. Your accession number is 2001\_\_\_\_\_.
- k. Class of Case 5: The first four digits of the accession number are the year of the patient's death.
  - Example: An accident victim enters the intensive care unit from the emergency department on December 31, 2002. The patient expires the following day, January 1, 2003. An autopsy shows a previously unsuspected bladder cancer. Accession number is 2003\_\_\_.

### 27. HOSPITAL SEQUENCE NUMBER

Item Length: 2
Data Type: Numeric
ACoS: Required
State Registry: Required

# Description

This is a required 2-character field for the number that indicates the chronological order of this primary tumor in relation to other reportable, independent, malignant and non-malignant neoplasms diagnosed in the patient's lifetime. The sequence number reflects all of a patient's reportable tumors, not just those seen at your hospital.

#### Rationale

This data item is used to distinguish among cases having the same accession numbers, to select patients with only one malignant primary tumor for certain follow-up studies, and to analyze factors involved in the development of multiple tumors.

# **Codes for Reportable Malignant or In Situ Primary Tumors:**

Code	Definition
00	One malignant or in situ primary only in the patient's lifetime
01	First of two or more independent malignant or in situ primaries
02	Second of two or more independent malignant or in situ primaries
03	Third of three or more independent malignant or in situ primaries
	(actual sequence of this malignant or in situ primary)
35	Thirty-fifth of thirty-five independent malignant or in situ primaries
99	Unspecified malignant or in situ sequence number or unknown

Note: When this field is left blank in the RMCDS program, the system defaults to code "00."

### Codes for Non-Malignant Tumors and Nonreportable Malignant or In Situ Tumors:

Code	Definition
60	Only one non-malignant primary
61	First of two or more independent non-malignant primaries
62	Second of two or more independent non-malignant primaries
	(Consecutive number of non-malignant primaries)
87	Twenty-seventh of twenty-seven independent non-malignant primaries
88	Unspecified number of neoplasms in this category

# **Definitions**

- a. <u>Hospital sequence number</u>: The code indicating the sequencing of reportable neoplasms in the patient's lifetime, according to the information and rules of the hospital registry.
- b. <u>Central sequence number</u>: The code indicating the sequencing of reportable neoplasms in the patient's lifetime, according to the information and rules of the central registry.
- c. Reportable-by-agreement tumors: Diagnoses not required by CoC but defined as reportable by the facility's cancer committee or the state registry. Such diagnoses may be benign, borderline, or malignant. Diagnoses required by the NPCR the Indiana State Cancer Registry, but not by CoC, include VIN III, VAIN III, and AIN.

Example:

The State Registry requires the hospital to report vaginal intraepithelial neoplasia, grade III (VAIN III, 8077/2). The cancer committee adds VAIN III to their reportable-by-agreement list and decides to accession and abstract these cases to comply with State requirements.

d. The following table\* illustrates the Indiana State Cancer Registry (ISCR) sequence number series by type of neoplasm.

Neoplasm	ISCR Sequence (Numeric Series)
Malignant (Behavior Code = 3) Includes AJCC T3, T4, or M1 Skin Squamous Cell and Basal Carcinomas diagnosed before 2003.	00-35
Juvenile Astrocytoma diagnosed 2001 and later (Report as 9421/3.)	00-35
In Situ (Behavior Code = 2). Includes VIN III, VAIN III, AIN III. Includes Cervix CIS/CIN III diagnosed before 1996.	00-35
Cervix CIS/CIN III diagnosed 1996-2002	98
Cervix CIS/CIN III diagnosed 2003 and later	60-87
PIN III	60-87
Borderline/Benign Intracranial and Central Nervous System	60-87
Other Borderline/Benign	60-87
Skin Squamous Cell and Basal Carcinomas diagnosed 2003 and later	60-87

<sup>\*</sup>Adapted from "NAACCR 2003 Implementation Workgroup Guidelines, January 2003."

#### Instructions

- a. Use codes 00-35 and 99 for reportable malignant or in situ neoplasms.
- b. Use codes 60-88 for non-malignant neoplasms and nonreportable malignant or in situ neoplasms.
- c. Use Code 00 only if the patient has a single malignant or in situ primary. If the patient develops a subsequent malignant or in situ primary tumor, change the code for the first tumor from 00 to 01, and number subsequent tumors sequentially.
  - Example 1: Use code 00 for a patient with no history of previous cancer is diagnosed within situ breast carcinoma January 13, 2003.
  - Example 2: Change the sequence to 01 for the January 13, 2003 breast carcinoma when the patient is diagnosed with a subsequent skin melanoma on July 30, 2003.
  - Example 3: Assign sequence 02 to the skin melanoma diagnosed on July 30, 2003 following a breast carcinoma diagnosed on January 13, 2003.

Use sequence 00 if there is no information available to indicate the patient has been diagnosed with an earlier primary malignancy. Assume the tumor being reported is the first. A history of surgery such as hysterectomy or colectomy should not be interpreted as evidence of an earlier malignancy without confirmation, since surgery is also performed to treat benign conditions.

d. Use sequence 99 only when there is information that suggests the possibility of an earlier malignancy, but the medical record does not document a definite diagnosis.

Example:

A patient is diagnosed in the reporting hospital with cancer of the colon. The medical record contains the statement, "The patient recently had a salivary gland tumor removed. The patient does not know if the lesion was malignant." The registry assigns sequence number 99 to the colon primary. The patient returns to the reporting facility a

year later for prostate cancer treatment. The medical record states, "The patient has a history of a malignant salivary gland tumor." Change the sequence number of the colon cancer from 99 to 02. Assign the sequence number 03 to the prostate cancer.

- e. If a patient has had a reportable tumor that the facility did not accession, it is accounted for in sequencing subsequent tumors.
  - Example 1: Your hospital diagnoses a patient with colon cancer. The patient has a history of kidney cancer diagnosed and treated elsewhere. Assign sequence number 02 to the colon cancer.
  - Example 2: A patient is diagnosed with breast cancer in 1985. Hospital A's reference date is 1987. In 2001, this patient has a primary of the lung. Assign sequence number 02 to the lung cancer.
- f. Sequence numbers should be reassigned if the facility learns later of an unaccessioned tumor that would affect the sequence.
- g. If two or more CoC required neoplasms are diagnosed at the same time, assign the lowest sequence number to the diagnosis with the worst prognosis. If no difference in prognosis is evident, the decision is arbitrary.
  - Example 1: A patient enters your facility with simultaneous invasive carcinoma of the cervix and invasive adenocarcinoma of the colon. Assign sequence number 01 to the colon primary and sequence number 02 to the cervix primary.
  - Example 2: A patient has simultaneous adenocarcinoma in situ in a colon polyp and squamous cell carcinoma in situ in a vocal cord polyp. Assign sequence numbers as you choose. Both primaries have similar prognoses.
- h. Use code 60 only if the patient has single non-malignant primary. If the patient develops a subsequent non-malignant primary tumor, change the code for the first tumor from 60 to 61, and assign codes to subsequent non-malignant tumors sequentially.
- i. The sequence codes for malignant/in situ and non-malignant cases are assigned independently. Assign sequence 60 to the first non-malignant tumor in a patient with a prior malignant or in situ primary with sequence number 00.
- j. The following types of cancer are single primaries. Any reappearance of the original disease is documented as a recurrence. Assign a sequence number to the first disease occurrence. Do not assign another sequence number to any subsequent occurrences of that same type of cancer.
  - Bladder primaries with morphology codes 8120-8131. (See page 100 for additional information on bladder primaries.)
  - Kaposi sarcoma (9140/3) of any site. (See pages 88 and 124 for additional coding rules.)
  - Invasive adenocarcinoma of prostate (C61.9).
  - Lymphoma and leukemia histologies that are determined from Appendix E-2 to refer to the same primary.
  - Non-malignant (behavior /0 or /1) primary intracranial and central nervous system tumors (C70.0-C72.9, C75.1-C75.3) within a single site (following the rules for primary site, including rules for laterality for paired sites) having the same histology (following the rules for histology.)

### 28. CLASS OF CASE

Item Length: 1
Data Type: Numeric
ACoS: Required
State Registry: Required

# Description

This is a required 1-character field for recording a code that classifies cases into analytic and non-analytic categories. Record the code that best describes where the patient was first diagnosed and first treated for cancer.

#### Codes

- Diagnosis at the reporting facility (since the registry's reference date) and all of the first course of treatment was performed elsewhere or the decision not to treat was made at another facility. Report to State.
- 1 Diagnosis at the reporting facility and all or part of the first course of treatment was performed at the reporting facility. Report to State.
- 2 Diagnosis elsewhere and all or part of the first course of treatment was performed at the reporting facility after the registry's reference date. Report to State.
- 3 Diagnosis and all of the first course of treatment was performed elsewhere. The patient presents at your facility with recurrence or persistent disease. Report to State if diagnosed in 1987 or later.
- Diagnosis and/or first course of treatment was performed at the reporting facility prior to the registry's reference date. Do Not Report to State unless the hospital's reference date is after 1987 and the case was diagnosed in 1987 or later.
- 5 Diagnosed at autopsy. Report to State.
- Diagnosis and all of the first course of treatment was completed by the same staff physician in an office setting. "Staff physician" is any medical staff with admitting privileges at the reporting facility. Report to State if the hospital collects class 6.
- 7 Pathology report only. The patient does not enter the reporting facility at any time for diagnosis or treatment. This category excludes cases diagnosed at autopsy. Report to State.
- 8 Diagnosis was established by death certificate only. Do Not Report to State, For State Use Only.
- 9 Unknown. Sufficient detail for determining Class of Case is not stated in the patient record. For State Use Only.

# **Definitions**

# a. Analytic Cases (codes 0, 1, and 2)

(These cases are included in treatment and survival statistics.)

- Patients diagnosed at the reporting facility since the reference date of the registry and/or:
- Patients who received all or part of their first course of treatment at the reporting facility since the reference date of the registry;
- Patients diagnosed prior to the registry's reference date whose first course of treatment continues at the reporting facility after the reference date.

# Notes:

All analytic cases must be reported.

If a patient has been accessioned into your registry as an analytic case (codes 0, 1, 2), do not reaccession or change the class of case code if the patient returns for a recurrence, subsequent treatment, or progression of disease involving the same primary.

# b. Non-analytic Cases (codes 3, 4, 5, 6, 7, 8, and 9)

(These cases are not usually included in routine treatment or survival statistics.)

- Patients diagnosed and receiving <u>all</u> of their first course of treatment at another facility before entering the reporting facility, or
- Patients diagnosed and/or treated at the reporting facility before the registry's reference date, or
- Patients diagnosed at autopsy, or
- Patients diagnosed and treated only in a staff physician's office, or
- Patients who never visit the hospital but for whom a tissue sample is pathologically evaluated and is positive for malignancy, or
- Diagnoses based on death certificates only.

**Note:** Only class 3, 4, 5 and 7 non-analytic cases diagnosed in 1987 or later should be reported. Class 6 cases should be reported if collected. The State Cancer Registry will collect class 8 cases. The data items to be reported for class 3 and 4 cases are listed in Chapter 3, page 22.

- c. **Class 0** cases are diagnosed at the reporting facility and are treated elsewhere. The term "elsewhere" refers to any facility not affiliated with the reporting facility, including freestanding cancer clinics and detection centers. These are reported to the State. Cases include:
  - Patients who choose to be treated elsewhere.
  - Patients who are referred to another facility for treatment for any reason. Reasons may include: Lack of special equipment; proximity of a patient's residence to the treatment center; financial, social, or rehabilitative considerations.

This category includes those patients diagnosed by x-ray or by clinical confirmation who were referred elsewhere for treatment.

- Example 1: A patient is clinically diagnosed or has a biopsy at your hospital that confirms a cancer diagnosis. The patient has no further work-up and is transferred to another hospital for work-up and treatment options. This would be a class 0 for the diagnosing hospital.
- Example 2: A cancer is identified at your hospital, but the staging work-up and treatment if performed at another hospital. This would be a class 0 for your hospital.
- d. **Class 1** cases are diagnosed and treated at the reporting facility. These are reported to the State. They fulfill one of the following treatment situations:
  - Patient received all or part of their first course of treatment at the reporting facility.
  - Patient refused any treatment.
  - Patient was not treatable or was given palliative care only because of age, advanced disease, or other medical condition.
  - Specific treatment was recommended but not received at the reporting facility and it is unknown if treatment was ever administered.
  - It is unknown if treatment was recommended or administered.
  - Patient was diagnosed at the reporting facility prior to the registry's reference date, and all or part of first course of treatment was received at the reporting facility after the registry's reference date.
  - Patient was first diagnosed and had staging work-up at the reporting facility and all or part of the first course of treatment was received in a staff physician's office.
  - Patient was diagnosed in a staff physician's office and was then treated at the reporting facility for all or part of the first course of therapy.

 Patient was diagnosed and treatment was planned at the reporting facility. Treatment was delivered elsewhere in accordance with the treatment plan.

Example: Your hospital diagnoses a patient with cancer and performs the work-up, but the hospital refers the patient to another hospital for chemotherapy.

- e. **Class 2** cases are diagnosed elsewhere. These are reported to the State. They also fulfill one of the following treatment situations:
  - The reporting facility provided part or all of the first course of treatment.
    - Example: A case was diagnosed at Hospital B, where the patient received radiation therapy. The patient then came to your hospital (Hospital A) for surgery within four months of the date that radiation therapy began.
  - The reporting facility provided palliative care in lieu of first course treatment or as part of the first course of treatment.
- f. Class 3 cases are patients who were diagnosed and received all of their first course of treatment elsewhere. They are then seen at the reporting facility with active (either recurrent or progressive) disease. While these are not required by ACoS, they are reportable to the State Registry if diagnosed in 1987 or later. They also fulfill one of the following treatment situations:
  - No information is available on their first course of treatment; patient is now treated or managed at the reporting facility.
  - The reporting facility is treating or managing the recurrence, progression, or subsequent treatment of a previously diagnosed malignancy.
  - The reporting facility developed a treatment plan or provided "second opinion" services, but the diagnosis and treatment were provided elsewhere.
- g. Class 4 includes cases that were diagnosed and/or received their first course of treatment at the reporting facility <u>before</u> the registry's reference date. The reporting facility manages or treats a recurrence or progression of that cancer <u>after</u> the registry's reference date. Assign a class of case 4 if it is unknown whether the reporting facility delivered the first course of treatment. These are not reported to the State, unless they meet the criteria described in the code list on page 79.
- h. **Class 5** refers to an incidental finding of cancer at autopsy. There was no suspicion of cancer before the autopsy. These are reported to the State.
- i. Class 6 includes patients who were both diagnosed and received all of their first course of treatment in a staff physician's office. If a physician holds multiple staff appointments, the physician must assign reporting responsibility to one of the facilities.
- j. Class 7 is used for path report only cases. The patient is never seen at the reporting facility.
- k. Class 8 should be used only by the central registry and includes diagnoses based on death certificates only.
- I. Class 9 should be used only by the central registry and includes:
  - Unknown if previously diagnosed.
  - Unknown if previously treated.
  - Previously diagnosed but date unknown.

### 29. FACILITY REFERRED FROM

Item Length: 10
Data Type: Numeric
Right Justify, Zero Fill
ACoS: Required
State Registry: Required

# **Description**

This is a required 10-character field for recording an identification number for the facility <u>from</u> which the patient was referred. This field is used to identify referral patterns and is important for tracking patients within the statewide database.

#### Codes

Record the facility identification number (FIN) assigned by the Commission on Cancer of the American College of Surgeons (ACoS). The FINs for Indiana hospitals are provided in Appendix D of this manual. A complete list of FINs is available on the American College of Surgeons Web site at <a href="http://www.facs.org/">http://www.facs.org/</a>.

# **Special Codes**

000000000 The patient was not referred to the reporting facility from another facility. 0099999999 The patient was referred but the referring facility's ID number is unknown.

**Note:** When this field is left blank in the RMCDS program, the system defaults to 0's.

#### Instructions

- a. Identify the referring facility <u>only</u> if the cancer being reported was definitively diagnosed and/or treated at the referring facility. Class of case is 2 or 3 at your facility. If the referring facility is a non-hospital facility that is not affiliated with any hospital, such as an independent surgery center, leave the field blank.
- b. Code 0's or blank for class 0, 1, and 6 cases.
- c. If the patient has been hospitalized for the malignancy in more than one hospital, record the code for the most recent hospitalization before this admission.

### 30. FACILITY REFERRED TO

Item Length: 10
Data Type: Numeric
Right Justify, Zero Fill
ACoS: Required
State Registry: Required

# Description

This is a required 10-character field for recording an identification number for the facility <u>to</u> which the patient is referred for definitive treatment after discharge from your facility. This field is used to identify referral patterns and is important for tracking patients within the statewide database.

#### Codes

Record the facility identification number (FIN) assigned by the Commission on Cancer of the American College of Surgeons (ACoS). The FINs for Indiana hospitals are provided in Appendix D of this manual. A complete list of FINs is available on the American College of Surgeons Web site at <a href="http://www.facs.org/">http://www.facs.org/</a>.

# **Special Codes**

0000000000 The patient was not referred to another facility.

0099999999 The patient was referred but the facility's ID number is unknown.

Note: When this field is left blank in the RMCDS program, the system defaults to 0's.

### Instructions

- a. Code 0's or blank for class 3 and autopsy-only cases.
- b. If the patient was referred to more than one hospital for definitive treatment, record the code for the first hospital to which the patient was referred.
- c. If the facility "referred to" is a non-hospital facility that is not affiliated with any hospital, such as an independent surgery center, leave the field blank.

# 31. IF DIAGNOSED ELSEWHERE, RECORD WHERE

Data Type: Text ACoS: N/A

State Registry: Required

# Description

This is a required text field for recording where the patient was diagnosed, if not at your facility. The item is required if applicable and available.

### Rationale

Text is needed to justify the codes selected for the data items and to record information that is not coded at all. The text is used for quality control and special studies.

### Instructions

a. Record the <u>name</u> of the facility or physician's office where the patient was diagnosed.

Examples: Name of another hospital, physician (by name) office, name of freestanding clinic, etc.

- b. If the patient was diagnosed in your facility, leave the field blank.
- c. Record "unknown" if the patient was diagnosed elsewhere, but it is unknown where.

### 32. DATE OF INITIAL DIAGNOSIS

Item Length: 8
Data Type: Numeric
ACoS: Required
State Registry: Required

#### Description

This is a required 8-character field for the date this primary cancer was diagnosed by a recognized medical practitioner. The month is recorded in the first two boxes, the day in the third and fourth boxes, and the year in the last four boxes (MM-DD-YYYY). A zero must precede single-digit months and day.

#### Codes

	<u>Month</u>	<u>Day</u>	<u>Year</u>
01 02 03	January February March	01 02 03	Use four-digit year (e.g., 2003) 9999 Year unknown
04	April		
05	May		
06	June	25	
07	July	26	
80	August	•••	
09	September	30	
10	October	31	
11	November	99 Day unknowi	า
12	December		
99	Month unknown		

#### Definition

This date refers to the date this cancer was diagnosed by any recognized medical practitioner. The first diagnosis is often clinical and may never be histologically confirmed. Refer to the list of terms that represent a clinical diagnosis in Chapter 4. Do not change the date of diagnosis when a later biopsy or cytology provides confirmation of a clinical diagnosis. Even if confirmed later, the diagnosis date refers to the date of the first clinical diagnosis and not to the date of confirmation. The date of the first clinical diagnosis provides a more accurate picture of the true survival time from date of diagnosis to death when determining survival statistics.

- Example 1: A March 12, 2003 mammogram reveals a mass in the upper-outer quadrant of a patient's right breast compatible with carcinoma. On March 20, 2003, the patient has an excisional breast biopsy that confirms infiltrating ductal carcinoma. Date of diagnosis is March 12, 2003.
- Example 2: A physician notes a prostate nodule that is suspicious for cancer during a May 11, 2003 physical examination. On June 15, 2003, an ultrasound guided needle biopsy of the prostate provides histologic confirmation of adenocarcinoma. Date of diagnosis is May 11, 2003.

#### Instructions

- a. If the physician says that in retrospect, the patient had cancer at an earlier date, use that earlier date as the date of diagnosis. When a tumor has been diagnosed as benign and a later medical or pathologic review of previous slides or x-ray films changes this to a diagnosis of a malignancy, the original date of diagnosis is considered to be the date of the <u>initial</u> slide or film review. In other words, the date of diagnosis is backdated.
  - Example: A patient has a total abdominal hysterectomy for endometriosis in January 2001. The patient is admitted with abdominal pain and distention in November 2002. A laparoscopy with omental biopsy shows metastatic cystadenocarcinoma. Pathologists review the 2001 hysterectomy specimen. They identify an area of cystadenocarcinoma in the left ovary. Date of diagnosis is January 2001 (01992001).

- b. The date of the histology, cytology, or tissue exam should be used <u>only</u> if that is the first date the cancer was diagnosed or if the date of initial, clinical diagnosis is unknown and it is the earliest alternative confirmation.
- c. If the date of initial clinical diagnosis is unknown but the diagnosis has been confirmed microscopically or through radiologic or other exam, use the date of the histology, cytology, tissue, or radiologic exam, whichever is earlier. In some cases, this may be a date prior to admission.
- d. Use the date of first cancer-directed therapy as the date of diagnosis if the cancer-directed therapy was started prior to the definitive diagnosis of cancer.
- e. The date of diagnosis for class of case code 5 (first diagnosed at autopsy) is the date of death.
- f. For patients diagnosed prior to admission to your facility, record the date of diagnosis from the referring hospital, practitioner, or clinic, if known. If the date is unknown, record the best estimate as described in paragraph g. below.
- g. If you do not know the exact date of diagnosis, estimate the date based on available information. Recording an approximate date is preferable to recording an unknown date.

Every attempt should be made to enter the month and day, even if an estimate is necessary. If there is no basis for approximation, code both month and day 99.

If necessary, estimate the year. Approximation of at least the year of diagnosis is preferred to coding the date as unknown. If approximation is impossible, code the year of diagnosis as 9999.

h. If information is limited to a description, use the following:

Descriptive Term Used	Date Code
Spring	April
The middle of the year	July
Fall	October
Winter	Try to determine if this means the beginning of the year (January) or the end of the year (December). Code as indicated.

# 33. PRIMARY SITE

Item Length: 3
Data Type: Numeric
ACoS: Required
State Registry: Required

#### Description

This is a required 3-character field for recording the topography (anatomic site) code that best describes the <u>primary</u> site of malignancy. <u>Metastatic lesions are NEVER coded in this field</u>. Review the entire medical record before assigning this code.

#### Instructions

- a. Enter the topography (anatomic site) code from the Topography section of the *International Classification of Diseases for Oncology*, Third Edition, 2000 (*ICD-O-3*)\* that best describes the <u>primary</u> site of the tumor. The topography code should first be located in the Alphabetic Index (pages 105-218). Then the specific topography should be located in the Topography Numerical List section (pages 45-65). The Alphabetic Index includes both topography and morphology terms.
  - \*Note: *ICD-O-3* is effective for cases diagnosed January 1, 2001 forward. Continue to use *ICD-O-2* for cases diagnosed prior to 2001.
- b. In the Alphabetic Index, all site (topography) codes are preceded by a "C." The "C" and the decimal point between the third and fourth characters are already on the abstract. Enter only the numeric code on the abstract.
  - Example: The code for upper-outer quadrant of breast is C50.4. Enter code 504 on the paper or computer abstract.
- c. Record the primary site as specifically as possible. For example, if the final diagnosis is "cancer of the colon," review other reports in the medical record (e.g., operative note, pathology report, radiology reports, and physician progress notes) to ascertain whether a more specific site within the colon can be identified.
- d. It is important that the <u>primary</u> site be coded, rather than a metastatic site. The primary site is the location where the cancer first developed, or the site of origin of a tumor. A metastatic site is the location to which the cancer has spread, or metastasized, from the primary site. Ask your physician advisor to identify the primary site or the most definitive site code if the medical record does not contain that information.
- e. Use the subcategory 8 (C\_\_.8) for single tumors that overlap the boundaries of two or more sub-sites and the point of origin is unknown.
  - Example 1: Code overlapping lesion (C10.8) when a large tumor involves both the lateral wall of the oropharynx (C10.2) and the posterior wall of the oropharynx (C10.3) and the point of origin is not stated.
  - Example 2: Code overlapping lesion of the bladder (C67.8) when one lesion involves the dome (C67.1) and the lateral wall (C67.2) and the point of origin is not stated.
- f. Use the subcategory 9 (C\_ \_.9) for multiple tumors that originate in one organ.
  - Example 1: Code bladder, NOS (C67.9) when multiple lesions arise in both the trigone (C67.0) and lateral wall (C67.2).
  - Example 2: Code lung, NOS (C34.9) when there are lesions in both the right middle lobe (C34.2) and the right lower lobe (C34.3) of lung.

- Example 3: Code breast, NOS (C50.9) when there are lesions in both the left lower-inner quadrant (C50.3) and the left lower-outer quadrant (C50.5) of a breast.
- g. If the specific site within an organ cannot be determined, code the primary site to the "NOS" (Not Otherwise Specified) category of the organ, organ system, or region. Refer to codes C76.0 to C76.8 (Other and III-Defined Sites) before coding C80.9 (Unknown primary site). If an unknown site is later specifically identified, the primary site code should be changed to the correct one.
  - Example: Your hospital clinically diagnoses a patient with carcinomatosis. The registry enters the case as an unknown primary (C80.9), carcinoma, NOS (8010/3), stage of disease unknown. Nine months later a paracentesis shows serous cystadenocarcinoma. The physician states that the patient has an ovarian primary. Change the primary site to ovary (C56.9), histology to serous cystadenocarcinoma (8441/3), and diagnostic confirmation to positive exfoliative cytology, no positive histology (2).
- h. Code leukemia, multiple myeloma, chronic myeloproliferative disorders, and myelodysplastic syndromes to bone marrow (C42.1), because blood cells originate in the bone marrow.

**Exception:** Code myeloid sarcoma (9930/3) to the site of origin. (See ICD-O-3 page 26 for coding rules.)

- i. Lymphomas
  - (1) Code lymphomas arising in lymphatic tissue or nodes to the site of origin. The lymphatic sites are lymph nodes(s) C77.\_, tonsil C09.\_, spleen C42.2, Waldeyer ring C14.2, and thymus C37.9.
  - (2) Code extralymphatic lymphomas (lymphatic cells in non-lymphatic organs such as intestine or stomach) to the organ of origin (intestine C26.0, stomach C16.0-C16.9).
  - (3) Code to lymph nodes, NOS (C77.9) when:
    - The site of origin is not identified for a lymphoma.
    - A patient has diffuse lymphoma and a primary site is unknown or not specified.
    - A lymphoma mass is identified as "retroperitoneal," "inguinal," "mediastinal," or "mesentery," and no specific information is available to indicate what tissue is involved.
    - Bone marrow metastases are present and the primary site of a lymphoma is unknown or not specified.
  - (4) Code to lymph nodes, multiple regions (C77.8) when multiple lymph node chains are involved with disease. Do not code a specific lymph node chain from multiple lymph node chains, even if the specific chain was biopsied.
  - (5) Code mycosis fungoides and cutaneous lymphomas to skin (C44. ).
  - (6) Carefully identify the origin of the tumor. Do not code the biopsy site or a metastatic site as the primary site. Lymphoma may be present in both an extralymphatic (extranodal) organ and one or more lymph node chain. Code the primary site as the extranodal organ or the lymph nodes, as directed by the managing physician or physician advisor.

Note: For purposes of analysis:

- Analyze the lymphatic sites C77.\_, C09.\_, C42.2, C14.2, and C37.9 together.
- Analyze extralymphatic lymphomas separately.
- i. Code Kaposi sarcoma to the site in which it arises. Code to skin (C44.9) if Kaposi sarcoma arises simultaneously in the skin and another site, and the primary site is not identified. Kaposi sarcoma is reported only once.

- k. Code to skin, NOS (C44.9) if a patient is diagnosed with metastatic melanoma and the primary site is not identified. Each occurrence of melanoma of the skin is a new/separate primary <u>unless</u> a physician says otherwise.
- If any of the following histologies appears with only an ill-defined site description (e.g., "abdominal" or "arm"), code it to the tissue in which such tumors arise rather than the ill-defined region (C76.\_) of the body, which contains multiple tissues.

Histology	ICD-O-3 Codes	Code to This Site
Melanoma	8720-8790	C44 Skin
Sarcoma except periosteal fibrosarcoma and dermatofibrosarcoma	8800-8811, 8813-8830, 8840-8921, 9040-9044	C49 Connective, Subcutaneous, and Other Soft Tissues
Mesenchymoma	8990-8991	C49 Connective, Subcutaneous, and Other Soft Tissues
Blood vessel tumors, lymphatic vessel tumors	9120-9170	C49 Connective, Subcutaneous, and Other Soft Tissues
Granular cell tumor and alveolar soft part sarcoma	9580-9582	C49 Connective, Subcutaneous, and Other Soft Tissues
Mesenchymal chondrosarcoma and giant cell tumors	9240-9252	C40, C41for Bone and Cartilage C49 Connective, Subcutaneous, and Other Soft Tissues
Mixed tumor, salivary gland type	8940-8941	C07 for Parotid Gland C08 for Other and Unspecified Major Salivary Glands

- m. Rule H on page 21 of ICD-O-3 discusses the topic of "Site-Specific Morphology Terms."
  - (1) If the patient record identifies a morphology term for which ICD-O-3 lists a specific topography code in parentheses, use this code if no definite site is identified or if only a metastatic site is identified.

Example: If the diagnosis hepatoma (8170/3) with no other statement about topography, code primary site as C22.0 (liver), since this morphology is always indicative of a primary malignancy in the liver.

(2) Some morphology codes list a specific topography code (C\_\_ . \_) to designate the <u>usual</u> primary site of origin for a particular neoplasm. If the <u>actual</u> primary site is different from the topography code listed, use the appropriate topography code of the actual site of origin and ignore the topography code listed next to the morphology code.

Example: If a patient has an infiltrating duct carcinoma of the pancreas (8500/3), code the primary as C25.9 (pancreas), even though "infiltrating duct carcinoma" has C50.\_ (breast) after it in the Alphabetic Index and the Morphology Numerical section of *ICD-O-3*, since breast is the usual site in which this histology arises.

n. For further guidelines on coding primary site, refer to the Introduction in *ICD-O-3* on pages 20-21. When the record is not clear, the physician should be contacted to determine the most definitive code to be used.

### **Rules for Determining Single vs. Multiple Sites**

For all solid malignant tumors diagnosed January 1, 2007 or later, use the SEER 2007 Multiple Primary and Histology Coding Rules.

a. A difference in the <u>third</u> character of the *ICD-O-3* topography code designates a separate site, with the exceptions listed under paragraph b. below.

Example: Separate sites and separate primaries:

Lower gum (C03.1)

Anterior floor of the mouth (C04.0)

b. The following table shows *ICD-O-3* site groupings that are to be regarded as one primary site when determining multiple primaries. These sites used to be in the same 3-digit site code group in *ICD-O-1*, but have been put into different 3-digit site groups in *ICD-O-2* and *ICD-O-3*. The groups are considered to be the same primary site in order to make valid historical comparisons between data collected under *ICD-O-1* and data collected under *ICD-O-3*.

ICD-O-3 CODES	SITE GROUPINGS
C01 C02	Base of tongue Other and unspecified parts of tongue
C05 C06	Palate Other and unspecified parts of mouth
C07 C08	Parotid gland Other and unspecified major salivary glands
C09 C10	Tonsil Oropharynx
C12 C13	Pyriform sinus Hypopharynx
C23 C24	Gallbladder Other and unspecified parts of biliary tract
C30 C31	Nasal cavity and middle ear Accessory sinuses
C33 C34	Trachea Bronchus and lung
C37 C38.0 C38.1-C38.3 C38.8	Thymus Heart Mediastinum Overlapping lesion of heart, mediastinum, and pleura
C51 C52 C57.7 C57.8-C57.9	Vulva Vagina Other specified female genital organs Unspecified female genital organs
C56 C57.0 C57.1 C57.2 C57.3 C57.4	Ovary Fallopian tube Broad ligament Round ligament Parametrium Uterine adnexa
C60 C63	Penis Other and unspecified male genital organs
C64 C65 C66 C68	Kidney Renal pelvis Ureter Other and unspecified urinary organs
C74 C75	Adrenal gland Other endocrine glands and related structures

- Example 1: A patient is diagnosed at Hospital A with a malignant tumor of the lateral wall of the oropharynx (C10.2). The patient is then referred to Hospital B, where further assessment reveals the tumor site of origin to be the tonsillar pillar (C09.1). When both of these cases are received at the State Registry, they will be consolidated into one cancer case, with tonsil (C09.1) being listed as the primary site.
- Example 2: A patient is diagnosed at Hospital A with a malignant tumor of the labia majora (C51.0). The patient is then referred to Hospital B, which reports the primary site as vagina (C52.9). To determine the primary site, review the pathology reports and consult with the attending physicians, surgeon, or registry advisor to identify the origin of the tumor. If there is a single lesion involving both sites and a site of origin cannot be determined, code to overlapping lesion of female genital organs (C57.8). If the tumor involves separate lesions and the site of origin cannot be determined, code to female genital tract, NOS (C57.9). These codes are for neoplasms of female genital organs whose point of origin cannot be assigned to any one of the categories C51 through C57.7, C58.
- c. A single lesion (tumor) is one primary even if the lesion crosses site boundaries.
  - Example: A patient has a large maxillary sinus tumor that extends into the sphenoid sinus. This is one primary: Maxillary sinus (C31.0).
- d. Sites may be anatomically separate and independent but are assigned to the same *ICD-O-3* topography code. These should be considered sub-sites of the same organ and recorded as a single site.
  - Example: Ulna (C40.0) and radius (C40.0) are treated as one site and one primary.
- e. A difference in the <u>fourth</u> character of the *ICD-O-3* topography code designates a sub-site of the same organ and is considered one site, with the exceptions listed below.
  - Example 1: Soft palate (C05.1) and uvula (C05.2) are treated as one site and one primary, either overlapping lesion of sub-sites of palate (C05.8) or palate, NOS (C05.9).
  - Example 2: Trigone of the bladder (C67.0) and lateral wall of the bladder (C67.2) are treated as one site and one primary, either overlapping lesion of sub-sites of the bladder (C67.8) or bladder, NOS (C67.9).

**Exception:** A difference in the <u>fourth</u> character of the *ICD-O-3* topography code designates a separate site <u>only</u> for the following site groups:

<ul> <li>Colon (see exception for polyps below)</li> </ul>	C18.0 – C18.9
<ul> <li>Anus/anal canal</li> </ul>	C21.0 - C21.8
<ul> <li>Pleura (visceral, parietal, NOS)</li> </ul>	C38.4
• Bone	C40.0 – C41.9
<ul> <li>Melanoma of the skin</li> </ul>	C44.0 – C44.9
<ul> <li>Peripheral nerves/autonomic nervous system</li> </ul>	C47.0 – C47.9
Connective Tissue	C49.0 – C49.9
<ul> <li>Non-malignant meninges</li> </ul>	C70.0 - C70.9, Behavior Code /0 or /1
<ul> <li>Non-malignant brain</li> </ul>	C71.0 - C71.8, Behavior Code /0 or /1
<ul> <li>Non-malignant spinal cord, cranial nerves, and other parts of central nervous system</li> </ul>	C72.0 – C72.8, Behavior Code /0 or /1

*Example:* Separate sites and separate primaries:

Sigmoid colon (C18.<u>7</u>) Transverse colon (C18.<u>4</u>)

**Note:** A non-specific site code, such as C18.9 (colon, NOS), and a specific site code, such as C18.2 (ascending colon), generally would not be recorded as separate sites for a single patient.

Exception: Colon Polyps

(1) Simultaneous lesions of adenocarcinoma or carcinoma and polyps (adenoma or adenomatous polyp) in <u>one segment</u> of the colon are a single primary.

- Example 1: A physician detects two lesions in the <u>same segment</u> of the colon. The pathology identifies the lesions as an adenocarcinoma (8140/3) and an adenocarcinoma in a(n) (adenomatous) polyp (8210/3). Code the histology to adenocarcinoma (8140/3). Adenocarcinoma in an adenomatous polyp (8210/3) is an earlier stage of disease than a frank adenocarcinoma.
- Example 2: Both an adenocarcinoma (8140/3) and an adenocarcinoma (in situ or invasive) in a(n) adenomatous polyp (8210) or an adenocarcinoma (in situ or invasive) in a (tubulo)villous adenoma (8261, 8263) arise simultaneously in the same segment of the colon or the rectum. Code as adenocarcinoma (8140/3).
- Example 3: Both a carcinoma (8010/3) and a carcinoma (in situ or invasive) in a(n) (adenomatous) polyp (8210) arise in the same segment of the colon within two months of diagnosis. Code as carcinoma (8010/3).
- (2) Polyps may be present in more than one segment of the colon. If the diagnosis reads "adenocarcinoma in multiple polyps," it is one primary, colon, NOS (C18.9).

Familial polyposis is a genetic disease characterized by polyps that increase in numbers and may cover the mucosal surface of the colon. The benign disease usually develops into adenocarcinoma in adenomatous polyposis coli or adenocarcinoma in multiple adenomatous polyps.

Patients with the histologies "adenocarcinoma in adenomatous polyposis coli" (8220/3) and "adenocarcinoma in multiple adenomatous polyps" (8221/3) have a different disease process than those patients with frank adenocarcinomas of the colon or typical colon polyps. If multiple segments of the colon, or the colon and rectosigmoid, or the colon, rectosigmoid and rectum are involved with adenocarcinoma in adenomatous polyposis coli or adenocarcinoma in multiple adenomatous polyps, it is a single primary. Code the primary site to colon, NOS (C18.9).

f. Paired Organ Sites

Each side of a paired organ is considered a separate site unless a physician determines one side is metastatic from the other.

**Exception 1:** The following are always single primaries:

- Simultaneous bilateral involvement of the ovaries with a single histology
- Simultaneous bilateral retinoblastomas
- Simultaneous bilateral Wilms tumors

(Diagnoses that occur at the same time or within two months of each other are considered simultaneous or synchronous.)

**Exception 2:** Disregard laterality for determination of single or multiple primaries for malignant (behavior or /2 or /3) tumors of the meninges (C70.\_); brain (C71.\_); and spinal cord, cranial nerves, and other parts of central nervous system (C72.\_).

Coding Tip: The Primary Site code must be between 000 and 809.

# 34. LATERALITY

Item Length: 1
Data Type: Numeric
ACoS: Required
State Registry: Required

## Description

This is a required 1-character field for recording a code that identifies the side of a paired organ or the side of the body on which the tumor originated. Laterality refers to the primary site only and should be coded independently for each primary. Metastatic involvement is not coded.

#### Codes

- 0 Not a paired organ or site; not applicable; unknown primary site
- 1 Right side is origin of primary
- 2 Left side is origin of primary
- 3 Only one side is involved; right or left origin unspecified
- 4 Bilateral involvement, side of origin unknown; stated to be a single primary.

Includes: Both ovaries involved simultaneously with a single histology

Bilateral retinoblastomas

Bilateral Wilms tumors

9 Paired site, but no information on laterality; midline tumor

**Note:** When this field is left blank in the RMCDS program, the system defaults to code zero (0).

#### Instructions

- a. If only one histologic type is reported and if both sides of a paired site are involved within two months of diagnosis, determine whether the patient had one or two independent primaries. Each side of a paired organ is considered a separate site unless a physician determines one side is metastatic from the other. *Exceptions:* See exceptions under paragraph f. on page 92.
  - (1) If there are two primaries, prepare two abstracts, recording the appropriate laterality and extent of disease for each.
  - (2) If there is only one primary (originated on one side and metastasized to the other), prepare a single abstract and code laterality according to the side where the primary originated. If it is not possible to determine the side where the primary originated, record laterality code 4 (bilateral involvement, lateral origin unknown).
- b. Record laterality for unknown primary site (C80.9) as 0 (not a paired organ or site).
- c. The following list identifies the paired organs or paired sites. For all sites that are <u>not</u> on the list, record laterality code 0 (not a paired organ; not applicable).

Use laterality code 1 – 9 for the following sites, except as noted. The listing includes only major categories. Code laterality for all subheadings included in *ICD-O-3* under these headings, unless specifically excluded. Exclusions should be coded as "0."

ICD-O-3 Prima	ıry
Site Code	Paired Organ or Site
C07.9	Parotid gland
C08.0	Submandibular gland (submaxillary gland)
C08.1	Sublingual gland
C09.0	Tonsillar fossa
C09.1	Tonsillar pillar
C09.8	Overlapping lesion of tonsil
C09.9	Tonsil, NOS
C30.0	Nasal cavity (excluding nasal cartilage and nasal septum – use code 0)
C30.1	Middle ear (Eustachian tube)
C31.0	Maxillary sinus
C31.2	Frontal sinus
C34.0	Main bronchus (excluding carina – use code 0)
C34.1-C34.9	Lung
	Note: C34.2 Middle lobe is on right side only – laterality code 1
C38.4	Pleura, NOS
C40.0	Long bones of upper limb, scapula, and associated joints (bones of arm)
C40.1	Short bones of upper limb and associated joints (bones of hand)
C40.2	Long bones of lower limb and associated joints (bones of leg)
C40.3	Short bones of lower limb and associated joints (bones of foot)
C41.3	Rib and clavicle (excluding sternum – use code 0)
C41.4	Pelvic bones and associated joints (excluding sacrum, coccyx, and symphysis pubis –
	use code 0)
C44.1	Skin of eyelid
C44.2	Skin of external ear
C44.3	Skin of other and unspecified parts of face (if site is non-paired or on midline, such as
044.5	chin, record laterality code 9)
C44.5	Skin of trunk (if site is non-paired or on midline, record laterality code 9)
C44.6	Skin of upper limb and shoulder
C44.7	Skin of lower limb and hip
C47.1	Peripheral nerves and autonomic nervous system of upper limb and shoulder
C47.2	Peripheral nerves and autonomic nervous system of lower limb and hip
C49.1	Connective, subcutaneous, and other soft tissues of upper limb and shoulder
C49.2	Connective, subcutaneous, and other soft tissues of lower limb and hip
C50.0-C50.9	Breast
C56.9	Ovary
C57.0	Fallopian tube
C62.0-C62.9	Testis
C63.0	Epididymis
C63.1	Spermatic cord (vas deferens)
C64.9 C65.9	Kidney, NOS Renal pelvis
C65.9 C66.9	Ureter
C69.0-C69.9	
C74.0-C74.9	Eye and adnexa (including lacrimal gland) Adrenal gland (suprarenal gland)
C74.0-C74.9 C75.4	Carotid body
075.4	Carolla body

For malignant and benign/borderline tumors diagnosed January 1, 2004 or later, the following central nervous system sites require a laterality code of 1-4 or 9:

C70.0 Cerebral meninges, NOS

C/U.U	Cerebrai meninges, NO
C71.0	Cerebrum
C71.1	Frontal lobe
C71.2	Temporal lobe
C71.3	Parietal lobe
C71.4	Occipital lobe
C72.2	Olfactory nerve

C72.3	Optic nerve
C72.4	Acoustic nerve
C72.5	Cranial nerve, NOS

d. The primary site codes listed below include both paired and a non-paired sub-sites.

Code	Paired Sub-Sites (Use laterality code 1, 2, 3, 4, or 9)	Non-Paired Sub-Sites (Use laterality code 0 or 9 as indicated below.)
C30.0	nasal cavity	nasal cartilage, nasal septum (0)
C34.0	main bronchus	carina (0)
C41.3	rib, clavicle	sternum (0)
C41.4	pelvic bones	sacrum, coccyx, symphysis pubis (0)
C44.3	skin of cheek, temple, eyebrow	skin of chin, face, nose, forehead (9)
C44.5	skin of axilla, breast, buttock	skin of abdomen, anus, back, chest (9)

Example: When coding for the main bronchus (C34.0), if bronchus (a paired organ) is the primary site, enter code 1, 2, 3, 4, or 9. Use code 0 if the carina (a non-paired organ) is the primary site.

## e. Text Documentation

Include laterality for applicable sites when recording the description of the primary site in the text area of the abstract. Use item 37 if reporting by paper abstract or *Primary Site Title* if recording in the RMCDS program. Staff at the State Cancer Registry will then know whether to override (bypass) an edit that identifies an inconsistency between site and laterality codes.

## 35. DIAGNOSTIC CONFIRMATION

Item Length: 1
Data Type: Numeric
ACoS: Required
State Registry: Required

## Description

This is a required 1-character field for recording a code that indicates how the cancer was confirmed or verified. It indicates whether at <u>any time</u> during the patient's disease course there was <u>microscopic</u> confirmation of the morphology of this cancer. You should note only one type of diagnostic confirmation, with code 1 (positive histology) as the best confirmation. This is a priority coding scheme, with code 1 taking precedence. Enter the lowest diagnostic confirmation code that applies. <u>A low number takes priority over all higher numbers</u>.

## **Codes and Definitions**

	Microscopically Confirmed					
1	Positive histology	Histologic confirmation (tissue microscopically examined).				
2	Positive cytology	Cytologic confirmation (no tissue microscopically examined; fluid cells microscopically examined).				
4	Positive microscopic confirmation, method not specified	Microscopic confirmation is all that is known. It is unknown if the cells were from histology or cytology.				
<u>Not</u> 5	Microscopically Confirmed Positive laboratory test/marker study	A clinical diagnosis of cancer is based on laboratory tests/marker studies that are clinically diagnostic for cancer. This includes alpha-fetoprotein for liver cancer and abnormal electrophoretic spike for multiple myeloma. Elevated PSA is non-diagnostic of cancer. If the physician uses the PSA as a basis for diagnosing prostate cancer with no other work-up, record as code 5. (Adapted from SEER.)				
6	Direct visualization without microscopic confirmation	The tumor was visualized during a surgical/endoscopic procedure only with no tissue resected for microscopic examination.				
7	Radiography and other imaging techniques without microscopic confirmation	The malignancy was reported by the physician from an imaging technique report only.				
8	Clinical diagnosis only (other than 5, 6, or 7)	The malignancy was reported by the physician in the medical record. Refer to ambiguous terminology in Chapter 4.				
<u>Cor</u> 9	nfirmation Unknown Unknown whether or not microscopically confirmed	A statement of malignancy was reported in the medical record, but there is no statement of how the cancer was diagnosed (usually Class of Case 3).				

#### Instructions

a. This data item includes the patient's <u>entire</u> disease course. Additional information may change the coding in this field for any case not coded 1 (positive histology). Change the field to the lower code if a preferable method confirms the diagnosis.

Example: A chest x-ray dated 12/01/02 diagnoses a probable lung cancer. The patient refuses a diagnostic work-up. The registry codes the diagnostic confirmation to radiography (code 7). The patient allows a lymph node biopsy on 2/03/03. The biopsy confirms small cell carcinoma. Change the diagnostic confirmation code to positive histology (code 1).

 The date of diagnosis does not have to agree with the date related to the type of diagnostic confirmation.

Example: A patient was clinically diagnosed on 4/08/03, diagnostic confirmation code 8. A biopsy (code 1), performed on 5/11/03, confirmed the cancer. The diagnostic confirmation code would be changed from 8 to 1, but the date of diagnosis would remain 4/08/03. Since the cancer was clinically diagnosed earlier than the biopsy was done, the diagnosis date will remain the same date as the clinical diagnosis and not the date of the biopsy.

- c. If diagnosis was confirmed at another hospital, e.g., class of case 2, enter the code for how the other hospital confirmed the diagnosis, if known, <u>unless</u> further confirmation with a lower code occurred at your facility. (e.g., If the other hospital performed a mammogram and your hospital performed a biopsy, code the biopsy.) If unknown, enter code 9.
- d. Some cytology specimens contain tissue. Some pathology/tissue specimens contain only cells or fluid aspiration. Read the report carefully to determine if the pathologist examined cells or tissue and code accordingly.

# **Definitions**

CODES	DEFINITIONS
1	<u>Tissue</u> specimens from biopsy, frozen section, surgery, autopsy, or dilatation and curettage (D & C).  Bone marrow biopsy and bone marrow aspiration, including those obtained by fine needle aspiration (FNA)* biopsies.  Hematologic confirmation of leukemia (e.g., peripheral blood smear).
2	Microscopic examination of <u>cells</u> removed from a neoplasm. Fine-needle aspiration (FNA)* is frequently used to obtain a cytologic specimen. The cells may be recovered from exudate, scrapings, secretions, or washings from tissue: sputum smears, bronchial brushings, bronchial washings, tracheal washings, prostatic secretions, breast secretions, gastric fluid, spinal fluid, peritoneal fluid, pleural fluid, urinary sediment, cervical and vaginal smears, and Papanicolaou's (Pap) smears.  Also includes paraffin-block specimens from concentrated spinal, pleural, or peritoneal fluid.
4	The case is reported as <u>microscopically confirmed</u> , but no information is provided about the method (histology, cytology).  Cases where the medical record or physician states the histology type, but there is no path report in the record.
5	Diagnosis of cancer based on certain <u>laboratory tests</u> or <u>marker studies</u> that are <b>clinically diagnostic</b> for cancer such as an abnormal electrophoretic spike for multiple myeloma or Waldenstrom macroglobulinemia. PSA is not clinically diagnostic for prostate cancer.
6	Use this code only in the absence of positive histology or cytology. Diagnosis made at surgical exploration or by endoscopy (e.g., colposcopy, mediastinoscopy, laparoscopy, colonoscopy, and esophagoscopy). Use only if such <u>visualization</u> is not supplemented by positive histology or positive cytology reports. Autopsy only case (only information is from gross autopsy report).
7	Use this code only in the absence of positive histology or cytology. Diagnosed by <u>radiology</u> , including ultrasound, computed (axial) tomography (CT or CAT scans), and magnetic resonance imaging (MRI).
8	Use this code only in the absence of positive histology or cytology.  Cases diagnosed by <u>clinical</u> methods not mentioned previously, e.g., a physician's statement that the patient has cancer would be included in this category.
9	Method of confirmation is <u>unknown</u> ; death-certificate-only cases.

\*Note: Since FNA may be used to obtain either tissue or cytology specimens, read reports carefully to determine which type of specimen was obtained.

<u>Coding Tips</u>: Diagnostic Confirmation must be coded 1, 2, or 4 if fifth digit in Histology/Behavior (Item 36b) is 2 (in situ). Diagnostic Confirmation should be coded 1, 2, or 4 if Grade/Differentiation (Item 36c) is 1, 2, 3, 4, 5, 6, 7, or 8.

## 36.A. HISTOLOGY

Item Length: 4
Data Type: Numeric
ACoS: Required
State Registry: Required

## Description

This is a required 4-character field for recording histologic (cell) type.

#### Instructions

For all solid malignant tumors diagnosed January 1, 2007 or later, use the SEER 2007 Multiple Primary and Histology Coding Rules.

- a. Enter the five-digit code from the Morphology Section of the *International Classification of Diseases* for Oncology, Third Edition, 2000 (*ICD-O-3*)\* that best describes the histologic (cell) type and behavior of this primary. First locate the morphology code in the Alphabetic Index (pages 105 218). Then locate the specific morphology code in the Morphology of Neoplasms Numerical List section (pages 69 104). Follow the coding rules outlined in *ICD-O-3* on pages 20 40.
  - \*Note: *ICD-O-3* is effective for cases diagnosed January 1, 2001 forward. Continue to use *ICD-O-2* for cases diagnosed prior to 2001.
- b. In the Alphabetic Index, all morphology codes are identified by an M- preceding the code number. Do not record the M on the abstract. Do not record the virgule (/ slash) on the abstract. All morphology codes begin with an 8 or 9.
  - Example: Infiltrating duct carcinoma is code M-8500/3. Record code 85003 on the abstract (paper or computer).

**Note:** Subsequent references to morphology codes will be stated without the preceding M- in the code.

- c. Review all pathology reports that describe the primary site before coding histology and behavior. Read each pathology report in its entirety. Although reports from the definitive cancer-directed surgery is usually the best, sometimes all of the positive tissue is removed at biopsy.
  - Example: The pathology report from a skin biopsy states malignant melanoma, NOS. At wide excision, no residual tumor was found. Code the histology from the biopsy report as malignant melanoma, NOS (8720/3).
- d. If no tissue or cytology specimen was obtained for a diagnosis of malignancy, but a recognized medical practitioner makes a clinical diagnosis of cancer, malignancy, malignant tumor, or malignant neoplasm, code to 8000/3 (Neoplasm, malignant). If the physician is more specific, use the more specific morphology code.

The codes for cancer, NOS (8000/3) and carcinoma, NOS (8010/3) are <u>not</u> interchangeable. If the physician says that the patient has carcinoma, code carcinoma, NOS (8010/3).

e. Code the final pathologic diagnosis.

**Exception:** At times, the final diagnosis is "Not Otherwise Specified" (NOS), e.g., carcinoma, NOS; melanoma, NOS; sarcoma, NOS; lymphoma, NOS; or malignant tumor, NOS. Code the histology from the microscopic description or comment if it describes a more specific histology (higher *ICD-O-3* code) such as adenocarcinoma, amelanotic melanoma, spindle cell sarcoma, etc. Record the <u>best</u> information found.

Example:

The final pathologic diagnosis is carcinoma (8010/3) of the prostate. The microscopic diagnosis states adenocarcinoma (8140/3) of the prostate, grade III. The more specific diagnosis, adenocarcinoma of the prostate, grade III (8140/33), should be coded.

f. Lymphomas may be classified by the Rappaport classification or the Working Formulation. If both systems are used to classify the disease, the term used to describe the lymphoma may differ, and the Working Formulation term should take precedence (*ICD-O-3*, pp. 13-18).

Example: In the Pathology report, the Working Formulation describes malignant lymphoma, large cell, immunoblastic (9684/3). The Rappaport classification describes malignant lymphoma, diffuse, histiocytic (9680/3). Use code 9684/3.

# **Histology Coding Rules**

a. When multiple terms describe a single histology, record the numerically highest code.

Example: In the diagnosis "transitional cell epidermoid carcinoma," transitional cell (8120/3) and epidermoid (8070/3) are both adjectives describing carcinoma. Record transitional cell (8120/3).

**Note:** If the diagnosis states "transitional cell <u>and</u> epidermoid carcinoma," "transitional cell with <u>areas of</u> epidermoid carcinoma," or "transitional cell <u>with a focus of</u> epidermoid carcinoma," the diagnosis would be interpreted as one of mixed or multiple histologies.

- b. The ICD-O-3 morphology code has five digits (e.g., 8500/3).
  - (1) When the <u>first three digits</u> of the *ICD-O-3* morphology codes are <u>identical</u>, the lesions are the <u>same histology</u>. Record the numerically higher code, as it is usually a more specific histology.
    - Example: A stomach biopsy is interpreted as adenocarcinoma, NOS (8140/3). The pathology from the resection identifies the tumor as linitis plastica (8142/3). Record the morphology code for linitis plastica (8142/3). (Refer to Rule K in the Introduction of ICD-O-3 on page 21 for more information.)
  - (2) When the <u>first three digits</u> of the *ICD-O-3* morphology code are <u>different</u>, the histologies are not the same. These lesion(s) have a mixed or multiple histology. Code using the rules under paragraph d. below, "Coding Mixed or Multiple Histologies."
    - **Exception 1:** Lymphatic and hematopoietic disease. Use the guidelines in Appendix E-2 (Prepared by: SEER Program, NCI, 02/28/2001) to determine which histologies represent single or multiple primaries.

**Exception 2:** If one malignancy is stated to be carcinoma, NOS; adenocarcinoma, NOS; sarcoma, NOS; or melanoma, NOS and the second lesion is a more specific term, such as large cell carcinoma, mucinous adenocarcinoma, spindle cell sarcoma, or superficial spreading melanoma, consider this to be a <u>single</u> histology.

**Note:** This rule applies when a nonspecific morphology and a specific morphology exist in a single lesion. Code as a single primary with the more specific morphology.

**Exception 3:** Code the following as single primaries with a single histology, even though the first three digits of the *ICD-O-3* morphology codes differ:

- Bladder lesions with morphology codes 8120-8130 (transitional cell and papillary transitional cell carcinomas) should be coded 8130/3, the combination code;
- Thyroid lesions with morphology codes 8260/3 (papillary carcinoma) and 8330/3 (follicular carcinoma) should be coded 8340/3, the combination code;

 Within each breast, lesions with morphology codes 8500/3 (ductal carcinoma) and 8520/3 (lobular carcinoma). Code such breast lesions to the combination code 8522/3. Use the combination code even if one of the lesions is in situ and the other invasive.

**Exception 4:** Use the following for the determination of single or multiple primaries of non-malignant (behavior /0 or /1) primary intracranial and central nervous system tumors (C70.0-C72.9, C75.1-C75.3).

- Two histologies appearing in the same grouping in the following table are the **same**. Code the more specific histology.
- A histology in the table and a histology not in the table that have the same first three digits are the **same**. Code its histology according to the rules for mixed histologies.
- Two histologies not appearing in the table but having the same first three digits are the **same**. Code its histology according to the rules for mixed histologies.

Choroid plexus neoplasms	9390/0, 9390/1
Ependymomas	9383, 9394, 9444
Neuronal and neuronal-glial neoplasms	9384, 9412, 9413, 9442, 9505/1, 9506
Neurofibromas	9540/0, 9540/1, 9541, 9550, 9560/0
Neurinomatosis	9560/1
Neurothekeoma	9562
Neuroma	9570
Perineurioma, NOS	9571/0

Example: A patient had a desmoplastic infantile astrocytoma (9412/1) in the right lateral ventricle (C71.5) diagnosed and treated thirteen years ago. Last week a ganglioma (9505/1) of the right lateral ventricle was diagnosed. The two tumors have the same subsite and laterality. They are both non-malignant and both histologies are in the same group in the table for non-malignant primary intracranial and central nervous system tumors. They represent a single tumor with the morphology, 9505/1.

(3) The <u>fifth digit</u> of the *ICD-O-3* morphology code is the behavior code. The behavior code is not used to determine multiple histologies. Lesion(s) may have a single histology with invasive and in situ components. This is a <u>single histology</u>. Code the behavior of the invasive component. If a single lesion has multiple histologies, one invasive and one in situ, code the invasive histology, even if the histology code for the in situ component is higher.

**Note:** This rule is also used for multiple lesions with the same histology. One lesion may be invasive and another lesion in situ, or each of the lesions may have invasive and in situ components.

- Example 1: Pathology of a breast mass shows infiltrating ductal carcinoma (8500/3) with a large intraductal component (8500/2). This is a single histology. Code the histology as infiltrating ductal (8500) and the malignant behavior (/3).
- Example 2: A patient has a colectomy and the pathology identifies two lesions in the sigmoid colon. The first lesion is an invasive adenocarcinoma (8140/3) and the second lesion is an adenocarcinoma in situ (8140/2). This is a single histology. Code the histology and behavior as adenocarcinoma, NOS (8140/3).

**Exception:** Two primary intracranial and central nervous system tumors (C70.0-C72.9, C75.1-C75.3) in which one is malignant (behavior of /2 or /3) and one is non-malignant (behavior of /0 or /1) are always separate primaries, regardless of timing.

c. Cancers are considered simultaneous if diagnosed within two months of each other.

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## d. Coding Mixed or Multiple Histologies

A single lesion with mixed or multiple histologic types is one primary. To code mixed or multiple histologies with the same behavior existing in one primary, use the following guidelines in this priority order:

- (1) Select a combination code
  - Example 1: The pathology report of a breast cancer describes mixed ductal (8500/3) and lobular carcinoma (8520/3). Record the combination code "ductal carcinoma and lobular carcinoma" (8522/3).
  - Example 2: The pathology report of a carcinoma of the cervix describes mixed adenocarcinoma and squamous cell carcinoma. Record the combination code "adenosquamous carcinoma" (8560/3).
- (2) Code the histology that comprises the majority of the tumor. Phrases such as "predominantly" and "with features of" are often used to identify the principal histology.
  - Example: A lung lesion is predominantly squamous cell carcinoma (8070/3) with focal areas of bronchiolo-alveolar adenocarcinoma (8250/3). A combination code does not exist. Record the predominant histology, squamous cell carcinoma (8070/3).

**Note:** The terms "with foci of," "areas of," or "elements of" describe minor areas of involvement. Do not code the histologies described by these terms unless there is a combination code.

(3) Code the histology with the highest ICD-O-3 morphology code.

Example: A patient with bladder cancer is diagnosed with mixed transitional cell carcinoma (8120/3) and epidermoid carcinoma (8070/3). There is no combination code for these histologies, and the pathology report does not identify a predominant histology. Record the highest morphology code, transitional cell carcinoma (8120/3).

f. Determining Multiple Primaries

For all solid malignant tumors diagnosed January 1, 2007 or later, use the SEER 2007 Multiple Primary and Histology Coding Rules.

Enter the case into the database as a single or multiple primary as documented by the physician. If physician determination is absent or unavailable, use the following guidelines, which are based on the *International Classification of Diseases for Oncology (ICD-O-3)*.

- (1) Determine whether there is a single lesion or multiple lesions.
- (2) Decide whether the tumor(s) involve a single site or multiple sites. Use the rules documented in the section for *Primary Site* (pages 87-92 of this chapter).
- (3) Decide whether the tumor(s) are a single histology or mixed/multiple histologies. Follow the "Histology Coding Rules" described above in this section.
- (4) Use the following table to decide whether the case should be abstracted as a single primary or multiple primaries.

LESIONS	SITE(S)	HISTOLOGY	VARIABLES	PRIMARY
Single	Single	Single		Single
	Single	Mixed/multiple		Single
Single or multiple	Single	Single	Different behavior codes, in situ (2) and invasive (3)	Single
	Same as previous site	Same as previous histology	Within two months of diagnosis	Recurrence of the original primary
	Same as previous	Same as previous	More than two months after	New primary unless physician states it is recurrent or metastatic.
	site	histology	diagnosis	Exceptions: Basal, squamous, basosquamous cell carcinoma of the skin; bladder; Kaposi sarcoma; adenocarcinoma of prostate; nonmalignant intracranial & CNS tumors.
Multiple	Single	Single	Simultaneous	Single
	Multiple	Single	Simultaneous	Multiple unless physician states it is metastatic.
				<b>Exceptions:</b> Ovaries (simultaneous bilateral), retinoblastoma, and Wilms tumor are single primaries.
	Single	Mixed/multiple	Simultaneous	Single
	Single	Multiple (Each tumor has a different histology.)	Simultaneous	Multiple
				<b>Exceptions:</b> Breast (lobular and ductal); bladder (transitional and papillary); thyroid (papillary and follicular).
	Multiple	Multiple	Simultaneous	Multiple

Example 1: Single lesion, single site, single histology, different behavior

The pathology report from the biopsy of a cervical lesion identified invasive carcinoma (8010/3) and squamous cell carcinoma in situ (8070/2). This is a single histology, because

carcinoma, NOS is a nonspecific morphology and squamous cell carcinoma is a specific morphology. Code the more specific histology and the invasive behavior (8070/3).

Example 2: Multiple lesions, single site, single histology, diagnosed within two months

A patient has a colectomy in August 2002 for an adenocarcinoma (8140/3). The physician biopsies the anastomotic site in September 2002. The pathologic examination confirms adenocarcinoma. This is a recurrence of the original tumor and should not be reported again.

Example 3: Multiple lesions, single site, single histology, diagnosed more than two months apart

A patient has surgery for a squamous cell carcinoma (8070/3) of the hard palate (C05.0) in January 2003. The physician biopsies another hard palate lesion in April 2003. Pathology confirms squamous cell carcinoma. There is no physician statement identifying the disease as recurrent or metastatic. This is a new primary and should be reported.

Example 4: Multiple lesions, single site, multiple histologies, diagnosed more than two months apart, **Exception** 

A transitional cell carcinoma (8120/3) of the trigone of the bladder (C67.0) was diagnosed in January of 2002. In May of 2003, a papillary transitional cell carcinoma (8130/3) of the bladder neck (C67.5) was diagnosed. Only the first bladder tumor would be reported, using a primary site code of C67.0 and a morphology code of 8120/3.

Example 5: Multiple lesions, multiple sites, single histology, simultaneous

The patient has masses in the esophagus and lung. Pathology identifies both lesions as squamous cell carcinoma, NOS (8070/3). Pathology does not identify either lesion as metastatic. There are two primaries: Esophagus (C15.9) and lung (C34.9).

Example 6: Multiple lesions, single site, multiple histologies, simultaneous

A patient has an adenocarcinoma (8140/3) at the gastroesophageal junction and a non-Hodgkin lymphoma (9591/3) in the body of stomach. The patient has two primaries.

Example 7: Multiple lesions, multiple sites, multiple histologies, simultaneous

A patient has a squamous cell carcinoma (8070/3) of the soft palate (C05.1) and an adenocarcinoma (8140/3) in Barrett esophagus (C15.9). The patient has two primaries.

# 36.B. BEHAVIOR

Item Length: 1
Data Type: Numeric
ACoS: Required
State Registry: Required

**Description** 

The fifth digit, which follows the slash after the histology code, is the behavior code. Behavior codes are listed in *ICD-O-3* page 66 and below. The State Cancer Registry requires only tumors ending in a fifth digit behavior code of /2 or /3 to be reported.

**Note:** *ICD-O-3* is effective for cases diagnosed January 1, 2001 forward. Continue to use <u>ICD-O-2</u> for cases diagnosed prior to 2001.

#### Codes

/0 Benign (do not report to State Registry)

## Exception:

Benign neoplasms of the brain and central nervous system diagnosed January 1, 2004 or later should be reported.

/1 Uncertain whether benign or malignant (do not report to State Registry)

Borderline malignancy

Low malignant potential

## Exceptions:

Juvenile astrocytoma, listed as 9421/1 in ICD-O-3, is required and should be reported as 9421/3; Borderline neoplasms of the brain and central nervous system diagnosed January 1, 2004 or later should be reported.

/2 Carcinoma in situ (report to State Registry)

Intraepithelial Noninfiltrating

Noninvasive

**Exceptions:** Preinvasive cervical neoplasia (in situ lesions and CIN III); prostatic intraepithelial neoplasia, grade III; and basal cell and squamous cell carcinoma of nongenital skin are not reportable if diagnosed 01/01/2003 or later.

- /3 Malignant, primary site (report to State Registry)
- /6 Malignant, metastatic site (<u>do not use</u>)
  Malignant, secondary site
- /9 Malignant, uncertain whether primary or metastatic site (do not use)

## **Instructions for Behavior Code**

- a. Since tumor registries include only primary, and not metastatic sites, behavior codes 6 and 9 should never be used. They are listed here for informational purposes only.
- b. Behavior codes /0 (benign) and /1 (uncertain or borderline) are <u>not</u> reportable to the State Cancer Registry unless listed under exceptions above. However, at the discretion of the cancer committee, a hospital may choose to collect some of these cases, which are called "reportable-by-agreement." The behavior codes are listed here for informational purposes only.
- c. The behavior code /6 indicates a metastatic site. If the only specimen available for diagnosis was from a metastatic site, code the histologic type of the metastatic site and code a /3 for the behavior code.

If the primary site is known, record the applicable topography code. If the primary site is unknown, the topography code should be C80.9.

Example: If the patient had a biopsy of the lung showing metastatic adenocarcinoma (8140/6), the primary site is unknown (C80.9). Code the histology to adenocarcinoma (8140/3).

d. "In situ" is a concept based upon histologic evidence. Therefore, clinical evidence alone cannot justify the usage of this term. If the fifth digit in Histology/Behavior is coded /2 (in situ), diagnostic confirmation should be 1, 2, or 4.

The following terms are synonymous with **in situ** (fifth digit behavior code /2):

(Adeno)carcinoma in an adenomatous polyp with no invasion of stalk

AIN III - Anal intraepithelial neoplasia, grade III (C21.1, 8077/2)

Bowen disease (8081/2)

CIN III - Cervical intraepithelial neoplasia, grade III (C53.\_, 8077/2)

Clark's Level 1 for melanoma (limited to epithelium)

Comedocarcinoma, noninfiltrating (C50., 8501/2)

Confined to epithelium

Hutchinson melanotic freckle, NOS (C44.\_, 8742/2)

Intracystic, noninfiltrating

Intraductal

Intraepidermal, NOS

Intraepithelial, NOS

Involvement up to but not including the basement membrane

Lentigo maligna (C44.\_, 8742/2)

Lobular neoplasia (C50.\_)

Lobular, noninfiltrating (C50.\_, 8520/2)

Noninfiltrating

Noninvasive

No stromal involvement or invasion (If there is stromal invasion, it is not in situ.)

Papillary, noninfiltrating or intraductal

Precancerous melanosis (C44.\_, 8741/2)

PIN III - Prostatic intraepithelial neoplasia, grade III (C61.9, 8148/2)

Queyrat erythroplasia (C60., 8080/2)

AJCC Stage 0

VAIN III – Vaginal intraepithelial neoplasia, grade III (C52.9, 8077/2)

VIN III – Vulvar intraepithelial neoplasia, grade III (C51.\_, 8077/2)

e. Code behavior as malignant (/3) if any invasion is present, no matter how limited. Any pathologic diagnosis qualified as "microinvasive" is not considered "carcinoma in situ" and behavior should be coded as malignant (/3).

Example: The pathology report from a hysterectomy reads "carcinoma in situ (8010/2) of the cervix with microinvasion." Code to invasive carcinoma (8010/3).

Coding Tips: If fifth digit in Histology/Behavior is coded /2 (in situ), laterality should be 0, 1, or 2

## 36.C. GRADE/DIFFERENTIATION

Item Length: 1
Data Type: Numeric
ACoS: Required
State Registry: Required

## Description

This is a required 1-character field to record the *ICD-O-3* code for the histologic grading or differentiation of solid tumors. Differentiation describes the tumor's resemblance to the normal tissue from which it arose. Well differentiated (Grade I) is the most like normal tissue. Grade/differentiation is the sixth digit of the histology code. For lymphomas and leukemias, this sixth digit may be used for identifying the cell origin.

## Codes

Code	Grade/Cell	Description
1	Grade I, 1, i	Well differentiated; differentiated, NOS
2	Grade II, 2, ii, I/III, or 1/3	Moderately differentiated, moderately well differentiated, intermediate differentiation
3	Grade III, 3, iii, II/III, or 2/3	Poorly differentiated
4	Grade IV, 4, iv, III/III, or 3/3	Undifferentiated, anaplastic
5	T-cell, T-precursor	Lymphomas and leukemias; T-cell, T-precursor
6	B-cell, pre-B, B-precursor	Lymphomas and leukemias; B-cell, pre-B, B-precursor
7	Null cell, non T-non B	Leukemias only; null cell, non T-non B
8	N K (natural killer) cell	Lymphomas and leukemias, natural killer cell (effective for cases diagnosed 01/01/1995 and after)
9	Grade/differentiation unknown	Grade/cell type not determined, not stated, or not applicable; unknown primaries; high grade dysplasia (adenocarcinoma in situ)

# Instructions

- a. Codes 5 8 define T-cell or B-cell origin for leukemias and lymphomas. T-cell, B-cell, or null cell classifications have precedence over grading or differentiation (codes 1-4). T-cell or B-cell should not be coded unless specified by the pathologist, or on a report from a marker study.
- b. Do not use "high grade," "low grade," or "intermediate grade" descriptions for lymphomas as a basis for differentiation. The terms are categories in the Working Formulation of lymphoma diagnoses and do not relate to the grade.

Example: "Intermediate grade malignant lymphoma, lymphocytic, poorly differentiated, diffuse" would be coded 9591/33, with the 6<sup>th</sup> digit "3" representing poorly differentiated.

c. Code the degree of differentiation or grade stated in the final pathologic diagnosis.

Example:

Microscopic Description: Moderately differentiated squamous cell carcinoma with poorly

differentiated areas.

Final Pathologic Diagnosis: Moderately differentiated squamous cell carcinoma.

Code: Moderately differentiated (2).

Exception: If the degree of differentiation or grade is not stated in the final pathologic diagnosis, use

the information from the microscopic description or comments.

d. Do not use the WHO grade to code this data item. For primary tumors of the brain and spinal cord diagnosed 01/01/2004 and later, record the WHO grade in the data item CS Site-Specific Factor 1.

- e. If no grade is given for astrocytomas, use code 9 (Unknown).
- f. If no grade is given for glioblastoma multiforme, use code 9 (Unknown).
- g. If more than one grade of tumor is specified, code to the highest grade, even if the highest grade is only a focus (RULE G in the Introduction of *ICD-O-3* on page 21).
  - Example 1: Code moderately to poorly differentiated carcinoma to poorly differentiated (3).

    Moderately differentiated is coded 2, and poorly differentiated is coded 3. Use the higher code.
  - Example 2: Code a combination of grades I and II carcinoma to moderately differentiated (2). Grade I is coded 1, and Grade II is coded 2. Use the higher code.
- h. When there is no tissue diagnosis, the grade of a tumor can be established through Magnetic Resonance Imaging (MRI) or Positron Emission Tomography (PET). Brain tumors can be graded using these methods. Code the grade or differentiation listed on the MRI or PET report if there is no tissue diagnosis of grade.
- i. Record the differentiation term over the grade term, if a differentiation is given.
- j. For sites other than breast, prostate, and kidney, code the tumor grade using the following priority order: 1) terminology; 2) histologic grade; 3) nuclear grade.
- k. Code the grade for in situ lesions if the information is available. If the lesion is both invasive and in situ, code only the invasive portion. If the invasive component grade is unknown, then code 9.
- Code the grade or differentiation from the pathologic examination of the primary tumor, not from metastatic sites.
  - Example: The pathology diagnosis for a biopsy of supraclavicular lymph nodes is "anaplastic adenocarcinoma compatible with lung primary." The histology/behavior/grade would be coded 8140/39 because the biopsy was not from the primary site.
- m. If the primary site is unknown, code the grade/differentiation as unknown (9).

## **Conversion/Prioritization Tables**

#### Coding Two-grade Systems

Two grade systems apply to colon, rectosigmoid junction, rectum (C18.0-C20.9), and heart (C38.0). Code these sites using a two-grade system; Low Grade (2) or High Grade (4). If the grade is listed as 1/2 or as Low Grade, use code 2. If the grade is listed as 2/2 or as High Grade, use code 4.

Code Terminology		Histologic Grade
2	Low grade	1/2
4	High grade	2/2

# Coding Three-grade Systems

Three grade systems apply to peritoneum (C48.1, C48.2), breast (C50.0-C50.9), endometrium (C54.1), fallopian tube (C57.0), prostate (C61.9), kidney (C64.9), and brain and spinal cord (C71.0-C72.9). For sites other than breast, prostate, and kidney, code the tumor grade using the following priority order: 1) terminology; 2) histologic grade; 3) nuclear grade as shown in the table below.

Code	Terminology	<b>Histologic Grade</b>	Nuclear Grade
2	Low grade, well to moderately differentiated	I/III or 1/3	1/3, 1/2
3	Medium grade, moderately undifferentiated, relatively undifferentiated	II/III or 2/3	2/3
4	High grade, poorly differentiated to undifferentiated	III/III or 3/3	2/2, 3/3

## Breast (C50.0-C50.9)

For breast cancers, code the tumor grade using the following priority order: 1) Bloom-Richardson (BR) (Nottingham) Scores; 2) Bloom-Richardson Grade; 3) Nuclear Grade; 4) Terminology; and 5) Histologic Grade as shown in the table below.

Code	BR Scores	BR Grade	Nuclear Grade	Terminology	Histologic Grade
1	3-5 points	Low grade	1/3, 1/2	Well differentiated	I/III or 1/3
2	6, 7 points	Intermediate grade	2/3	Moderately differentiated	II/III or 2/3
3	8, 9 points	High grade	2/2, 3/3	Poorly differentiated	III/III or 3/3

# Kidney (C64.9)

For kidney cancers, code the tumor grade using the following priority rules: 1) Fuhrman Grade; 2) Nuclear Grade; 3) Terminology (well differentiated, moderately differentiated); 4) Histologic Grade. These prioritization rules do not apply to Wilms tumor (8960/3).

## Prostate (C61.9)

For prostate cancers, code the tumor grade using the following priority order: 1) Gleason Score (This is the sum of the patterns, e.g., if the pattern is 2-4 the score is 6); 2) Terminology; and 3) Histologic Grade as shown in the table below.

Code	Gleason Score (sum of primary & secondary patterns)	Terminology	Histologic Grade
1	2, 3, 4	Well differentiated	I
2	5, 6	Moderately differentiated	II
3	7, 8, 9, 10	Poorly differentiated	III

## **Tumor Grade and AJCC Staging**

The AJCC Cancer Staging Manual may state that a specific histology is to be considered a specific grade. Follow AJCC instruction for "Staging" only. Follow ICD-O-3 rules and rules in this section for assigning a grade to tumors recorded in your abstract.

The AJCC Cancer Staging Manual identifies the following sites in which tumor grade/differentiation is used to assign the AJCC stage group:

Site	ICD-O-3
Heart, mediastinum, and pleura (soft tissue)	C38.0 - C38.8
Bone	C40.0 - C41.9
Peripheral nerves and autonomic nervous system (soft tissue)	C47.0 - C47.9
Retroperitoneum and peritoneum (soft tissue)	C48.0 - C48.8
Connective, subcutaneous, and other soft tissues	C49.0 - C49.9
Prostate (Stage IA only)	C61.9
Thyroid (undifferentiated carcinoma only)	C73.9

<u>Coding Tips</u>: If Grade/Differentiation is coded 5, 6, or 8 histology code must in the lymphoma range (9590/3 to 9729/3) or the leukemia range (9800/3 to 9948/3).

If Grade/Differentiation is coded 7, histology code must be in the leukemia range (9800/3 to 9948/3).

## 37. DESCRIPTION OF DIAGNOSIS

**RMCDS Items:** 

Primary Site Title, Histology Title, Dx Procedure Pathology

Data Type: Text

State Registry: Required

ACoS: N/A

#### Description

This is a required text field in the paper abstract and the corresponding required RMCDS fields for recording a narrative description of the primary site, histologic type, behavior, and grade. Facilities using other types of registry software should follow their vendor's instructions for recording text about the site and histology.

#### Rationale

Text is needed to justify the codes selected for the data items and to record information that is not coded at all. The text is used for quality control and special studies.

## Instructions

- a. Record a brief, but specific, description of the site of origin for the tumor being reported. Include laterality if applicable. Use standard abbreviations to conserve space if necessary and if each abbreviation has a clear meaning and only one interpretation.
  - Example 1: Upper outer quadrant (UOQ) of right (RT) breast.
  - Example 2: Splenic flexure of colon.
- b. Record a brief, but specific, description of the histologic type, behavior, and grade of the tumor being reported. Use standard abbreviations to conserve space if necessary and if each abbreviation has a clear meaning and only one interpretation.
  - Example 1: Infiltrating duct and lobular carcinoma (ca).
  - Example 2: Moderately well differentiated (MWD) adenocarcinoma (adenoca) in adenomatous polyp.
  - Example 3: Malignant lymphoma, lymphocytic, poorly differentiated (PD), nodular.
  - Example 4: Superficial spreading melanoma.
  - Example 5: Astrocytoma, stage III.
  - Example 6: Adult T-cell leukemia.
- c. In the Description of Diagnosis or the RMCDS Dx Procedure Pathology field, record any additional pertinent information from cytology and histopathology reports. In RMCDS it is not necessary to repeat information recorded in the primary site and histology text fields. Include, as applicable:

Date(s) of procedure(s)

Type(s) of tissue specimen(s)

Gross tumor size

Extent of tumor spread

Involvement of resection margins

Number of lymph nodes involved and examined

Differential diagnoses considered and any ruled out or favored.

d. Facilities using paper abstracts to report should also attach copies of medical record documentation (such as pathology reports and operative reports) that identifies the site and histology information for the primary being reported. However, text describing the site and histology must be completed by all reporting facilities.

## 38. TUMOR SIZE

Item Length: 3
Data Type: Numeric
Right Justified, Zero Fill
ACoS: Required\*
State Registry: Required\*

\*For cases diagnosed on or before 12/31/2003

# **Description**

This is a required 3-character field to record the largest dimension, or the diameter, of the <u>primary</u> tumor in millimeters. Right justify and enter leading zeros.

**Note:** Code this data item for cases diagnosed on or before December 31, 2003. For cases diagnosed on or after January 1, 2004 code tumor size using *CS Tumor Size*.

#### Codes

000	No mass or tumor found; e.g., a tumor of a stated primary site is not found, but the tumor has
	metastasized.
001-988	Exact size in millimeters; for melanoma, depth in hundredths of millimeters.
989	989 millimeters or larger; melanomas greater than or equal to 9.89 mm in depth.
990	Microscopic focus or foci only, no size is given.
998	Tumor involvement of specified esophageal, stomach, colorectal, lung and main stem
	bronchus, and breast primaries. See coding instructions.
999	Unknown; size not stated; not stated in the patient record; not applicable.

#### Instructions

a. Code the exact size of the primary tumor in millimeters (mm).

# Conversion/Rounding

 To convert centimeters to millimeters, move the decimal point one digit to the right (or multiply the centimeters by 10).

> 0.1cm = 1 mm 1 cm = 10 mm 3.2 cm = 32 mm

- Use code 001 for tumors less than 1 mm in size
- Formulas for converting inches to millimeters are listed below.

394 inch = 10 mm 1 inch = 25 mm

## Exception:

- For melanomas, code the depth of invasion in HUNDREDTHS of millimeters for the following sites: skin (C44.0-C44.9), vulva (C51.0-C51.9), penis (C60.0-C60.9), scrotum (C63.3), and conjunctiva (C69.0). A 1-mm depth would be recorded as 100.
- Use code 989 for melanomas of the above sites that are 9.89 mm or greater in depth.
- b. Recording pathologic size versus clinical size:
  - (1) Use the size documented on the pathology report when:
    - The pathologist identifies the size of a completely excised primary tumor.
    - The surgical margins were grossly free of disease (there may be microscopic involvement).
  - (2) Use the clinical size when:
    - The primary tumor was not surgically excised.
    - The primary tumor was excised but the margins were grossly involved.
    - The primary tumor was excised but the pathology report does not specify tumor size.
    - The patient was treated with radiation therapy, chemotherapy, hormone therapy, or immunotherapy before the primary was surgically excised. Code the size of the tumor prior to the therapy.

Use the clinical tumor size documented in the following reports/examinations (listed in priority order): operative report, scans, x-ray, or physical examination.

 Code the size of the primary tumor, rather than the size of the specimen, polyp, ulcer, cyst, or metastasis.

Example: The patient had an excisional breast biopsy. Pathology report states that the specimen measures 2 cm x 3 cm, but does not state the actual size of the tumor. Do not use the specimen size of 2 cm x 3 cm. Code the size from the operative report, mammography, or the physical exam.

- d. Code the largest dimension or diameter of a tumor when multiple measurements are recorded.
- e. Record the size of the largest tumor when a patient has more than one tumor in the same primary site.
- f. When a tumor has both in situ and invasive components, record the size of the invasive component only. For purely in situ tumors, code the size as stated.
- g. Do not report the tumor size based on a biopsy unless the biopsy removed all of the primary tumor. Code the size of the residual tumor if an excisional biopsy is performed, and residual tumor at the time of resection of the primary site is found to be larger than the excisional biopsy.
- h. Do not add pieces or chips together to create a whole. They may not be from the same location, or they may represent only a very small portion of a large tumor. A clinical size may be documented in a physical exam, an ultrasound of the prostate, or a cystoscopy of the bladder.
- i. Record 998 when the following terms describe tumor involvement in these specific sites:

• Colorectal (C18.0 – C20.9) Familia	e; widespread; 3/4 or more; linitis plastica al/multiple polyposis (histology 8220 or 8221 with a
• Lung and main stem bronchus Diffuse (C34.0 – C34.9)	rior code of /2 or /3) e, entire lobe or lung e; widespread; 3/4 or more of breast; inflammatory

- j. Record **999** for the following:
  - Tumor size is unknown or not documented in the patient record.
  - Prostatic chips or bladder chips are the only measurement documented in the patient record.

carcinoma

- If only one size is given for a mixed in situ and invasive tumor.
- For a needle biopsy specimen.
- The patient was treated with radiation therapy, chemotherapy, hormone therapy, or immunotherapy before the primary was surgically excised and no clinical size prior to therapy is documented.
- For the following sites and diseases:
  - Hematopoietic, reticuloendothelial, immunoproliferative, myeloproliferative, and myelodysplastic diseases. (C42.0, C42.1, C42.3, C42.4 and/or M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)
  - Hodgkin and non-Hodgkin lymphomas, including mycosis fungoides of skin (9700) and Sezary disease (9701)
  - Kaposi sarcoma (9140)
  - Letterer-Siwe disease (9754)
  - Multiple myeloma (9732)
  - Unknown or ill-defined primary site or sites (C76.0-C76.8, C80.9)

# Codes with Examples:

- 013 A patient with lung cancer is described as having a 1-cm nodule in the right upper lobe and a 1.3-cm nodule in the right middle lobe of the lung. Code the size of the largest nodule as 13 mm.
- 044 A pathology report describes the tumor size as 3 x 4.4 x 2.5 cm. Code the largest diameter of the tumor as 44 mm.
- 001 A pathology report describes a specimen that measures 2 x 3 cm with a focus (microscopic) of infiltrating carcinoma. Code microscopic focus as 1 mm.
- 010 A pathology report describes a breast mass as 2- x 1.5-cm intraductal carcinoma and a 1-cm nodule of infiltrating ductal carcinoma. Code the invasive component as 10 mm.
- 045 A patient with melanoma of the skin has the primary tumor excised, and the thickness of the tumor was measured as 0.45 mm. Code the depth of invasion in HUNDREDTHS of mm or 45.
- 001 The patient had a colonoscopy with polypectomy. The pathology report describes "a 1 x .5 cm polyp with a microscopic focus of adenocarcinoma in situ." <u>Do not</u> record 10 mm as tumor size. Use the size given in the conversion table below for microscopic (001 mm).

#### **Conversion Table**

If a descriptive term rather than the actual size is documented, use the following list for size conversion.

Example: For microscopic foci of tumor, record tumor size as 001.

OBJECT	СМ	ММ	OBJECT	СМ	ММ	OBJECT	СМ	ММ
Frui	ts		Pea, split	00.9	009	Money		
Apple	07.0	070	Nut	s		Dime	01.0	010
Apricot	04.0	040	Almond	03.0	030	Dollar, half	03.0	030
Cherry	02.0	020	Chestnut	04.0	040	Dollar, silver	04.0	040
Date	04.0	040	Chestnut, horse	04.0	040	Nickel	02.0	020
Fig, dried	04.0	040	Hazel	02.0	020	Penny	01.0	010
Grape	02.0	020	Hickory	03.0	030	Quarter	02.0	020
Grapefruit	10.0	100	Peanut 01.0 010 Other					
Kumquat	05.0	050	Pecan	03.0	030	Ball, golf	04.0	040
Lemon	08.0	080	Walnut	03.0	030	Ball, Ping-Pong	03.0	030
Olive	02.0	020	Miscellaneous Food			Ball, tennis	06.0	060
Orange	09.0	090	Doughnut	09.0	090	Baseball	07.0	070
Peach	06.0	060	Egg	05.0	050	Fist	09.0	090
Pear	09.0	090	Egg, bantam	04.0	040	Marble	01.0	010
Plum	03.0	030	Egg, goose	07.0	070	Match head	00.9	009
Tangerine	06.0	060	Egg, hen	03.0	030	Pencil eraser	00.9	009
Vegeta	bles		Egg, pigeon	03.0	030	030 Microscopic 00.1		
Bean	01.0	010	Egg, robin	02.0	020	1 centimeter	01.0	010
Bean, lima	02.0	020	Lentil	00.9	009	1 inch	02.5	025
Pea	00.9	009	Millet	00.9	009	.394 inches	01.0	010

Note: Text Documentation

In the RMCDS abstract screen, an optional text field labeled *Description of Size* follows the *Tumor Size* field. Facilities that choose to complete this field should briefly record the text from the medical record documentation used to code *Tumor Size*. If the *Description of Size* field is not completed, tumor size information should be recorded in any text field describing the site and histology. Facilities using other types of registry software should follow their vendor's instructions for recording text.

## 39. REGIONAL NODES POSITIVE

Item Length: 2
Data Type: Numeric
Right Justified, Zero Fill
ACoS: Required
State Registry: Required

Item revised for cases diagnosed 01/01/2007 and later.

## Description

This is a required 2-character field to record the number of <u>regional</u> lymph nodes the pathologist examined and described as metastatic, or positive for malignancy. For numbers less than 10, enter a leading zero. Beginning with cases diagnosed on or after January 1, 2004, this item is a component of the Collaborative Staging System (CS).

## Codes

- 00 All regional nodes examined are negative.
- 01-89 1-89 regional nodes are positive. Code exact number of nodes positive.
- 90 90 or more regional nodes are positive.
- Positive aspiration or core biopsy of regional lymph node(s) was performed.
- 97 Positive regional lymph nodes are documented, but the number is unspecified.
- 98 No regional nodes were examined.
- 99 It is unknown whether nodes are positive; not applicable; not stated in the patient record.

Example: The pathology report reads 11 out of 17 nodes examined were found to contain metastatic squamous cell carcinoma. Record 11 in the *Regional Nodes Positive* field.

#### Instructions

- a. Record the total number of <u>regional</u> lymph nodes removed as part of the <u>first</u> course of treatment, <u>examined by the pathologist</u>, and reported to contain cancer. The number of regional lymph nodes positive is cumulative from all procedures that removed lymph nodes through the completion of surgeries in the first course of treatment.
  - Do not record positive distant lymph nodes removed as part of the first course of treatment.
  - Do not code positive regional lymph nodes removed to establish recurrence or progression of disease.
  - Do not code nodes assessed by clinical examination only and stated to be positive.
- b. Record the number positive regardless of whether the patient received preoperative treatment.
- c Use code 90 when 90 or more nodes are positive.
- d. Use code 95 when the cytology or histology from a lymph node aspiration is positive for malignant cells.
- e. Use code 97 for any combination of positive aspirated, biopsied, sampled, dissected lymph nodes if the number of involved nodes cannot be determined on the basis of cytology or histology.
- f. Use code 98 when no nodes were removed for examination or if a lymph node drainage area was removed, but no lymph nodes were found.
- g. Use code 99 when it is unknown whether lymph nodes were examined.
- h. Use code 99 for the following primary sites and histologies:
  - Placenta (C58.9)
  - Brain and cerebral meninges (C70.0, C71.0-C71.9)
  - Other parts of central nervous system (C70.1, C70.9, C72.0-C72.5, C72.8-C72.9)
  - Hodgkin and non-Hodgkin lymphoma (9590-9729) except 9700/3 and 9701/3

- Hematopoietic, reticuloendothelial, immunoproliferative, myelodysplastic or myeloproliferative neoplasms (9731-9734, 9740-9742, 9750-9758, 9760-9762, 9764-9769, 9800-9801, 9805, 9820, 9823, 9826-9827, 9831-9837, 9840, 9860-9861, 9863, 9866-9867, 9870-9876, 9891, 9895-9897, 9910, 9920, 9930-9931, 9940, 9945-9946, 9948, 9950, 9960-9964, 9970, 9975, 9980, 9982-9987, 9989)
- Unknown or ill-defined primary sites (C76.0-C76.5, C76.7-C76.8, C80.9) and C42.\_ and C77.\_
  other than hematopoietic, reticuloendothelial, immunoproliferative, myeloproliferative, and
  myelodysplastic neoplasms as listed above, Hodgkin and non-Hodgkin lymphomas as listed above,
  and Kaposi sarcoma 9140/3.
- i. The number of positive regional lymph nodes cannot exceed the number of nodes recorded in the *Regional Lymph Nodes Examined* field.
- j. Unidentified lymph nodes included with the resected primary site specimen are to be considered regional, rather than distant, lymph nodes.
- k. "Lymphatic invasion" means that tumor was found in lymph channels, but does not necessarily mean that the lymph node was invaded. It is a prognostic indicator, however, since it indicates that the tumor is present in the pathway by which it spreads.
- I. Refer to the SEER Summary Staging Guide or the AJCC Cancer Staging Manual to identify site-specific regional lymph nodes. If there is a discrepancy between the two references on what are considered regional lymph nodes, follow the rules in the SEER guide, unless your cancer program is ACoS approved. ACoS approved cancer registries should defer to the AJCC Manual.

**Note:** While *Regional Nodes Positive* must be confirmed by pathologic examination, Summary Stage can be based on a clinical assessment of regional nodes. Summary Stage may be correctly coded as node positive (Stage 3 or 4) when no pathologic examination of nodes has been performed. If Summary Stage is based on clinically positive nodes, please document the information in a text field so that State Registry staff can override any error messages generated by computer edits.

Coding Tips: If Nodes Positive is 00 – 97, Diagnostic Confirmation (Item 35) should be coded 1, 2, or 4.

## 40. REGIONAL NODES EXAMINED

Item Length: 2
Data Type: Numeric
Right Justified, Zero Fill
ACoS: Required
State Registry: Required

Item revised for cases diagnosed 01/01/2007 and later.

# Description

This is a required 2-character field to record the total number of <u>regional</u> lymph nodes that were examined by a pathologist. For numbers less than 10, enter a leading zero. Removal of regional lymph nodes and removal of the primary tumor may be performed in the same or in separate operative episodes. Beginning with cases diagnosed on or after January 1, 2004, this item is a component of the Collaborative Staging System (CS).

#### Codes

- 00 No regional lymph nodes were examined.
- 01-89 1-89 regional lymph node(s) were examined. Code the exact number of regional lymph nodes examined.
- 90 Ninety or more regional lymph nodes were examined.
- 95 No regional lymph node(s) were removed but aspiration or core biopsy of regional lymph node(s) was performed.
- 96 Regional lymph node removal was documented as a sampling and the number of lymph nodes is unknown/not stated.
- 97 Regional lymph node removal was documented as a dissection and the number of lymph nodes is unknown/not stated.
- 98 Regional lymph nodes were surgically removed but the number of lymph nodes unknown/not stated and not documented as sampling or dissection; nodes were examined but the number is unknown.
- 99 It is unknown whether nodes were examined; not applicable or negative; not stated in the patient record.

## Notes:

For cases diagnosed through 1997, see page 145 in the June 1998 State manual.

When this field is left blank in the RMCDS program, the system defaults to code zeros (00).

#### Instructions

- a. Record the total number of <u>regional</u> lymph nodes removed as part of the <u>first</u> course of treatment and <u>examined by the pathologist</u>. The number of regional lymph nodes examined is cumulative from all procedures that removed lymph nodes through the completion of surgeries in the first course of treatment.
  - Do not record distant lymph nodes removed as part of the first course of treatment.
  - Do not code regional lymph nodes removed to establish recurrence or progression of disease.
  - Do not code nodes assessed by clinical examination. The statement, "the neck was negative for nodes," should be interpreted (coded) as "no nodes examined."
- b. Record the number examined regardless of whether the patient received preoperative treatment.
- c. Use code 00 when no nodes are removed for examination or if a lymph node drainage area was removed, but no lymph nodes were found. (Use code 98 for the *Regional Lymph Nodes Positive* field when no nodes are examined.)
- d. Use code 95 when a lymph node aspiration was performed, but no nodes were removed.
- e. Use code 96 if a lymph node biopsy was performed and the number of nodes is not known. Code the number of nodes removed, if known.

- f. Use code 98 if lymph nodes are aspirated and other lymph nodes are removed.
- g. Use code 99 when it is unknown whether lymph nodes were examined.
- h. Use code 99 for the following primary sites and histologies:
  - Placenta (C58.9)
  - Brain and cerebral meninges (C70.0, C71.0-C71.9)
  - Other parts of central nervous system (C70.1, C70.9, C72.0-C72.5, C72.8-C72.9)
  - Hodgkin and non-Hodgkin lymphoma (9590-9729) except 9700/3 and 9701/3
  - Hematopoietic, reticuloendothelial, immunoproliferative, myelodysplastic or myeloproliferative neoplasms (9731-9734, 9740-9742, 9750-9758, 9760-9762, 9764-9769, 9800-9801, 9805, 9820, 9823, 9826-9827, 9831-9837, 9840, 9860-9861, 9863, 9866-9867, 9870-9876, 9891, 9895-9897, 9910, 9920, 9930-9931, 9940, 9945-9946, 9948, 9950, 9960-9964, 9970, 9975, 9980, 9982-9987, 9989)
  - Unknown or ill-defined primary sites (C76.0-C76.5, C76.7-C76.8, C80.9) and C42.\_ and C77.\_
    other than hematopoietic, reticuloendothelial, immunoproliferative, myeloproliferative, and
    myelodysplastic neoplasms as listed above, Hodgkin and non-Hodgkin lymphomas as listed above,
    and Kaposi sarcoma 9140/3.
- i. The number of regional lymph nodes examined must be equal to or greater than the number of nodes recorded in the *Regional Lymph Nodes Positive* field.
- j. Refer to the SEER Summary Staging Guide or the AJCC Cancer Staging Manual to identify site-specific regional lymph nodes. If there is a discrepancy between the two references on what are considered regional lymph nodes, follow the rules in the SEER guide, unless your cancer program is ACoS approved. ACoS approved cancer registries should defer to the AJCC Manual.

# 41. SITE(S) OF DISTANT METASTASIS

Item Length: 3 Data Type: Numeric Left Justified, Zero Fill ACoS: N/A

State Registry: Required

## Description

This is a required 3-character field that allows you to record up to 3 separate sites of distant metastasis. If fewer than three sites exist at the time of diagnosis, enter the correct code for the site of metastasis and enter zeros in the remaining spaces (left justify).

## Codes

- 0 None; no distant metastasis
- 1 Peritoneum
- 2 Lung (Pulmonary)
- 3 Pleura
- 4 Liver (Hepatic) only
- 5 Bone (Osseous)
- 6 Central nervous system (CNS)
- 7 Skin
- 8 Distant lymph nodes
- 9 Other, generalized, carcinomatosis, disseminated, site not specified, unknown distant site

# **Definitions**

CODES	DEFINITIONS
0	No distant metastases present.
1	Peritoneum, including peritoneal surfaces of all structures within the abdominal cavity and/or positive ascitic fluid. Peritoneum includes all supportive and protective serous membranes covering the organs ("visceral") and the surfaces ("parietal") of the abdominal cavity. This includes mesenteries, serosa (visceral peritoneum), greater omentum, and lesser omentum. Ascites is the accumulation of serous fluid in the abdominal cavity and is included here if positive.
2	Lung, including the visceral pleura.
3	Pleura, including the pleural surface of all structures within the thoracic cavity and/or positive pleural fluid.
4	Liver only.
5	Bones other than the primary site.
6	Central nervous system includes brain and spinal cord, but NOT the external eye.
7	Skin other than the primary site.
8	Includes lymph nodes not classified as regional. Refer to the SEER Summary Staging Guide for a description of lymph nodes that are considered distant for a particular site. The AJCC Cancer Staging Manual also lists regional and distant lymph nodes. However, if the AJCC manual does not agree with the SEER guide, use the SEER guide to determine which nodes are regional, unless your cancer program is ACoS approved. ACoS approved registries should defer to the AJCC Manual.
9	Bone marrow metastases, carcinomatosis, generalized disease, unknown primary.
	Systemic diseases such as leukemia, multiple myeloma, plasma cell myeloma, reticuloendotheliosis, and Letterer-Siwe disease should be coded 999.
	Includes cases where it is known there is distant metastasis, but site(s) is (are) unknown or unspecified. It also includes other sites not specified in this coding list.

#### Instructions

- a. Enter the code for each site of distant metastasis. A maximum of three sites may be coded. If there are more than three sites of distant metastasis, code three of the sites.
- b. Relationships Between Summary Stage and Site(s) of Distant Metastasis:
  - (1) If any sites of distant metastasis are recorded in this field, Summary Stage must be 7.

**Exception:** For all lymphoma cases, code *Sites of Distant Metastasis* 999, including Summary Stage local (1) and regional (5) cases.

(2) If Summary Stage is coded 7 (distant), *Sites of Distant Metastasis* should **not** be coded "000" (a 0 in each space), except for ACoS approved registries when the exception described below applies.

Exception: When the description for "distant" in the SEER Summary Staging Guide is inconsistent with the M1 (distant metastases) definitions in the AJCC Cancer Staging Manual, registries in ACoS approved programs should code Sites of Distant Metastasis according to the M1 definitions. For some sites, such as ovary, a Summary Stage "distant" may not qualify as an AJCC stage "distant." For such cases, Sites of Distant Metastasis should be coded as "000" even though Summary Stage is coded 7 (distant). This may result in an error message that should be overridden when edits are applied to the record.

- (3) If Summary Stage is coded 9 (unstaged, unknown, or unspecified), record 999 (a 9 in each space).
- (4) If Summary Stage is coded anything (codes 0, 1, 2, 3, 4, 5) besides 7 or 9, Sites of Distant Metastasis **should** be coded "000" (a 0 in each space).

**Exception:** For all lymphoma cases, code *Sites of Distant Metastasis* 999, including Summary Stage local (1) and regional (5) cases.

- c. Record 999 (a 9 in each space) if carcinomatosis is present, for disseminated disease, leukemia, Hodgkin or Non-Hodgkin lymphoma, multiple myeloma, Letterer-Siwe disease, reticuloendotheliosis, chronic myeloproliferative disorders, myelodysplastic syndromes, unknown stage, and unknown primaries.
- d. If code "9" is recorded to identify a metastatic site not addressed by codes 1-8 (rather than for disseminated disease), the remaining two spaces should be coded to any other metastatic site(s) or "0" (none), as applicable. The site coded to "9" should be identified more specifically by documenting it in the *Substantiate Stage* text field (Item 43).
- e. A biopsy may distinguish the source of distant disease in a patient with multiple primaries. If there is no histologic or cytologic confirmation, consult the physician to help identify which primary has metastasized. If the physician is unable to decide which primary has metastasized, code both primaries as having metastatic disease. If at a later date, the primary is identified, update the codes as appropriate.

# 42. SUMMARY STAGE 2000 (GENERAL SUMMARY STAGE)

Item Length: 1
Data Type: Numeric
ACoS: Required\*
State Registry: Required\*

## Description

This is a required 1-character field for recording a code that indicates the extent of cancer spread. The only way to determine the correct Summary Stage is by referring to the SEER Summary Staging Manual, 2000. You cannot determine the correct code without using this manual. The Summary Stage must be completed on all cases. Refer to the SEER Summary Staging Manual for complete guidelines on assigning Summary Stage to be used in this section.

**Note:** SEER Summary Staging Manual, 2000 is effective for cases diagnosed January 1, 2001 forward. Continue to use SEER Summary Staging Guide, 1977 for cases diagnosed prior to 2001.

#### Codes

- 0 In situ
- 1 Localized
- 2 Regional by direct extension
- 3 Regional to lymph nodes only
- 4 Regional by direct extension and to lymph nodes (combination of codes 2 and 3)
- 5 Regional, NOS
- 7 Distant metastases/systemic disease
- 9 Unstaged, unknown, or unspecified

#### **Definitions and Rules**

- a. Summary Stage of disease is a clinical judgment of the extent of cancer spread and should include all information available through completion of surgery(ies) in the first course of treatment or within four months of diagnosis in the absence of disease progression, whichever is longer. Stage does not change as the disease progresses. Metastasis that is known to have developed after the original diagnosis was made should be excluded.
- b. For all sites, the extent of disease is based on pathologic, operative, and clinical assessment. If there is a discrepancy between the pathology report and the operative report, the priority for assessing extent of disease is based on pathologic, operative, then clinical findings, respectively. Gross observations at surgery are particularly important when not all malignant tissue is removed. If no surgery is performed, use all diagnostic or radiological evidence and therapeutic procedures available in the medical record to determine the Summary Stage, if enough information is provided.
- c. Autopsy reports are used in coding extent of disease by applying the same rules for inclusion and exclusion.
- d. The terms used to describe tumor involvement are sometimes ambiguous. Chapter 4 lists terms that may be interpreted as tumor involvement or non-involvement.
- e. There is only one correct Summary Stage for each tumor. If the State Cancer Registry receives reports from multiple hospitals for the same case and the Summary Staging doesn't match, State Registry staff will select and save only the most appropriate Summary Stage based on the best information available.

<sup>\*</sup> Required by ACoS only for cancers diagnosed through 12/31/2003 with no AJCC staging schema. Required by the State Registry for all cases diagnosed through 12/31/2003.

CODES	TERM	DEFINITIONS
0	In Situ	Not progressed through the basement membrane of the organ involved (non-invasive tumor). Only organs with an epithelium can be "in situ;" this excludes muscles, connective tissues, fat (adipose tissue), bones, cartilage, ligaments, tendons, blood cells and vessels, and lymph nodes and vessels.
		Used only when the pathology report demonstrates that involvement is confined to the basement membrane and the tumor is described as noninvasive, preinvasive, noninfiltrating, intraductal, intraepithelial, or in situ. See Item 36b, page 106 for additional terms that are synonymous with "in situ."
		If there is evidence of lymph node involvement of a tumor described as in situ, it would indicate that an area of invasion was missed, and it is <u>not</u> an in situ lesion.
		Be cautious regarding needle biopsy of the lung. The specimen may be from the edge of the lesion and be reported as "in situ," when actually an invasive lesion of advanced stage is present.
		Coding Tips: If the fifth digit of Histology/Behavior code (Item 36b) is /2 (in situ), Summary Stage must be coded 0 (in situ). If Summary Stage is coded 0, the behavior code must be /2.
1	Localized	Limited to the site of origin; progression through the basement membrane, but not beyond the walls of the organ involved. Includes tumors confined to the primary organ site or described as microinvasive or "early" invasion.
		Stage I (localized) lymphomas are included here.
2	Regional by direct extension	Tumors not confined to the organ of origin (primary site), but which extend into adjacent organs or tissues by passing through the wall of the primary organ. If the tumor spreads to a NON-contiguous organ from the primary site, it is no longer regional.
3	Regional	Tumor involvement with regional lymph nodes only.
	to lymph nodes only	Includes lymph nodes in the area (region) of the primary tumor that contain tumor and the cancer has not spread to other organs by direct extension. Do not use evidence of palpable nodes as described in the physical examination of the patient to increase the stage of disease unless the record clearly states that in the physician's judgment, the node is involved. Nodes described as "fixed" or "matted" are considered involved. "Mass in the mediastinum, retroperitoneum, and/or mesentery" (with no specific information as to tissue involved) is considered involvement of lymph nodes.
		Any unidentified lymph nodes included with the resected primary site specimen are to be considered regional, rather than distant, lymph nodes.
		Regional lymph nodes are not palpable for inaccessible sites such as bladder, kidney, lung, liver, and ovary. The best description concerning regional lymph nodes will be the surgeon's evaluation at the time of exploratory surgery or definitive surgery, or x-ray and CT scans if no surgery is performed.
4	Regional by direct extension and to lymph nodes	Tumor invades adjacent organ(s) and regional lymph nodes (codes 2 and 3).
5	Regional, NOS	Regional, not other wise specified. (The stage is known to be regional, but the medical record is unclear as to whether it is through direct extension or lymph node involvement.)
		Stage II (regional) lymphomas are included here.

CODES	TERM	DEFINITIONS			
7	Distant	Cases that have (1) Direct extension beyond adjacent organs or tissues, (2) Metastases to distant lymph nodes, and/or (3) Metastases to distant site(s) via the circulatory or lymphatic system or by "seeding" or implantation to parts remote from the primary tumor. This category usually includes brain, liver, bone, and lung metastases.			
		Code the following primary sites as having distant metastases/systemic disease (7): Leukemia, multiple myeloma, plasma cell myeloma, reticuloendotheliosis, immunoproliferative neoplasms, myeloproliferative and myelodysplastic neoplasms, and Letterer-Siwe disease.			
		Stage III and IV (distant) lymphomas are included here.			
		Coding Tip: Summary Stage must be 7 if Sites(s) of Distant Metastasis (Item 41) is 9 (indicating distant sites). Exception: For lymphomas, Sites of Distant Metastasis are always coded as 999, regardless of Summary Stage.			
9	Unstaged	No information or death certificate only.			
		Includes the following:  1) Unknown primaries (C80.9) 2) Unstaged or unspecified primaries 3) Class 4 cases when the stage at initial diagnosis is unknown 4) Patients with recurrent disease seen for the first time at your hospital after your reference date, unless the stage at initial diagnosis is known.			

See additional definitions in the Glossary at the end of the Policy and Procedure Manual.

#### Instructions

- a. To determine the Summary Stage code, using the *SEER Summary Staging Manual*, look up the section for the original site where the cancer started. Each such section is divided into general staging categories (localized, regional, and distant).
  - (1) The "Localized" category lists the layers or parts of the primary organ. If the cancer is contained within these layers, it is considered localized (code 1).
  - (2) The "Regional" category is divided into "Direct Extension" and "Lymph Nodes" subcategories. If the cancer has spread to any of the adjacent organs or sites listed in the Direct Extension subcategory, it is considered regional by direct extension (code 2). If the cancer has spread to the regional lymph nodes specified, it is considered regional to lymph nodes (code 3). If the cancer has spread to adjacent organs and to regional lymph nodes, use code 4, a combination of codes 2 and 3.
  - (3) The "Distant" category lists the most common, but not all, sites of distant spread for each primary site. If the cancer has spread to an organ that is not directly touching the original primary organ, it is considered distant by direct extension or metastasis (code 7). Positive lymph nodes that are not in the region of the original primary site are considered distant lymph nodes (Summary Stage code 7). Use the SEER Summary Staging Guide to determine if a lymph node is regional or distant. The AJCC Cancer Staging Manual (the TNM coding book) is also a good reference to use when determining Summary Stage, even if you do not actually assign TNM codes. The AJCC manual often lists lymph nodes that are considered regional (vs. distant lymph nodes) and includes illustrations that may clarify the various layers of an organ (e.g., colon).

b. In the SEER Summary Staging Guide 1977, the categories localized, regional by direct extension, and distant are subdivided into further categories, although these subdivisions are not used at the State Registry. The categories are not subdivided in the SEER Summary Staging Manual 2000. For cases diagnosed prior to January 1, 2001, the subdivisions should be coded as follows:

CODES	SUMMARY STAGE	DESCRIPTION OF SUBDIVISION
1	Localized	L1, L2, L3, LX
2	Regional by direct extension	R1, R2
7	Distant metastases/systemic disease	D1, D2

c. Unknown primaries (C80.9) should be coded 9 (unstaged), even if the unknown primary has been diagnosed from a metastatic site.

Example: A patient with an unknown primary site (C80.9) has metastases in the brain and liver. Although at least one of these sites has to be a metastatic site <u>distant</u> from the original primary (since brain and liver are not adjacent to each other), Summary Stage should be coded 9 (unknown) to be consistent with ACoS rules in the FORDS. Sites of Distant Metastasis (Item 41) should be coded 999, even though there are known metastases to the brain and liver. If you want to document these metastatic sites, record them in Item 43, Substantiate Stage.

# d. Kaposi Sarcoma

- (1) For cases diagnosed January 1, 2001 forward, use the Kaposi sarcoma staging scheme found in the SEER Summary Staging Manual, 2000.
- (2) For cases diagnosed prior to 2001 (according to advice from NAACCR), since there is no disease-specific staging scheme for Kaposi sarcoma in the SEER Summary Staging Guide, 1977, registries may use the scheme appropriate for the primary site. If the primary site is skin, use the "skin other than melanoma" scheme. Although this is not ideal, it does allow grouping of cases based on how extensive the Kaposi sarcoma was at diagnosis.

Example: A single lesion of the skin with no lymph node or other involvement would be Summary Stage 1 (local). A patient with either a lesion on both the right and left legs, or widespread skin lesions, would be Summary Stage 7 (distant).

## e. Malignant Melanoma

Clark's Level and Breslow's Depth of Invasion are other staging systems for malignant melanoma. Use the following conversion when the medical record reports only Clark's Level or Breslow's Depth of Invasion. (Use only for melanoma of skin, vulva, penis, and scrotum.)

Summary Stage Code	Summary Stage	Clark's Level	Breslow's Depth of Invasion	Extent of Disease
0	In situ	I	No invasion	Intraepidermal
1	Localized	II	≤ 0.75 mm	Invasion of papillary dermis
1	Localized	III	> 0.75 - ≤ 1.50 mm	Invasion of papillary-reticular dermal interface
1	Localized	IV	> 1.50 - ≤ 4.0 mm	Invasion of reticular dermis
2*	Regional extension*	V	> 4.0 mm	Invasion subcutaneous tissue (through entire dermis)

<sup>\*</sup>Summary stage 1, Localized, in Summary Stage 1977 for cases diagnosed prior to 2001.

# Coding Tips:

- If Regional Nodes Positive (Item 39) is 1 to 97, Summary Stage Should be coded 3, 4, 5, 7, or 9.
- If Sites of Distant Metastasis (Item 41) include any code from 1 to 8, Summary Stage must be 7 (distant metastasis).
- If Sites of Distant Metastasis (Item 41) are coded 000 (indicating NO distant metastasis), Summary Stage CANNOT be 7 (distant metastasis).

# f. Lymphomas

The staging system for lymphomas is provided below. It is based on the 1971 Ann Arbor classification and should be used for anatomic staging of Hodgkin and Non-Hodgkin lymphomas. Appendix E-1 has some tips for coding lymphomas and leukemias.

Note: The only valid Summary Stage codes for lymphomas are codes 1, 5, 7, or 9.

Example: A Stage II lymphoma is coded as Summary Stage 5, not 2.

Summary Stage Code	Summary Stage	AJCC Staging	Extent of Disease
1	Localized	1	Involvement of a single lymph node region.
1	Localized	I <sub>E</sub>	Localized involvement of a single extralymphatic organ or site.
5	Regional	II	Involvement of two or more lymph node regions on the same side of the diaphragm.
5	Regional	II <sub>E</sub>	Localized involvement of a single associated extralymphatic organ or site and its regional nodes with or without other lymph node regions on the same side of the diaphragm. Note: The number of lymph node regions involved may be indicated by a subscript (e.g., II3).
7	Distant	III	Involvement of lymph node regions on both sides of the diaphragm.
7	Distant	III <sub>E</sub>	Involvement of lymph node regions on both sides of the diaphragm that may also be accompanied by localized involvement of an extralymphatic organ or site.
7	Distant	III <sub>S</sub>	Involvement of lymph node regions on both sides of the diaphragm that may also be accompanied by involvement of the spleen.
7	Distant	III <sub>E+S</sub>	Involvement of lymph node regions on both sides of the diaphragm that may also be accompanied by localized involvement of an extralymphatic organ or site and involvement of the spleen.
7	Distant	IV	Disseminated (multifocal) involvement of one or more extralymphatic organs with or without associated lymph node involvement, or isolated extralymphatic organ involvement with distant (non-regional) nodal involvement.
9	Unspecified	99	Unstaged, unknown, unspecified.

## **OVERVIEW OF COLLABORATIVE STAGING (CS)**

The complete instructions and site-histology defined codes are available in the *Collaborative Staging Manual and Coding Instructions (CS Manual)*, Version 01.04.00. Part I provides general instructions and the instructions and codes for generic (non site-specific) items. Part II contains the site-specific instructions and codes. The *CS Manual* and related information is available electronically on the AJCC Web site at http://www.cancerstaging.org.

Collaborative Staging was designed for registrar use.

- It relieves registrars from the necessity of staging a single case according to more than one staging system.
- It avoids the problems that can occur when it is necessary to consider multiple pieces of information simultaneously to assign a single code.
- The derived stage codes are ideally suited for data analysis because of the consistency that can be obtained with objectively recorded, identically processed data items.

## **Effective Date**

Collaborative Staging (CS) is to be used for cases diagnosed on or after January 1, 2004. It is not to be used for cases diagnosed prior to that date.

# **How Collaborative Staging Works**

For Collaborative Staging, registrars code discrete pieces of information once and the CS computer algorithm derives the values for AJCC T, N, M, and Stage Group; Summary Stage 1977; and Summary Stage 2000.

The following CS data items are coded by the registrar. Items with an asterisk (\*) have site-specific variations for some codes.

CS Tumor Size\*

CS Extension\*

CS Tumor Size/Ext Eval

CS Lymph Nodes \*

CS Reg Lymph Nodes Eval

Regional Lymph Nodes Examined

Regional Lymph Nodes Positive

CS Mets at DX\*

CS Mets Eval

CS Site-Specific Factors 1-6, for some sites\*

The CS Algorithm produces the output items listed below. The derived AJCC items are separate from the physician-coded items, and the derived Summary Stage items are separate from the manually coded items collected by the CoC in the past. The derived items must never be manually altered.

Derived AJCC T

Derived AJCC T Descriptor

Derived AJCC N

Derived AJCC N Descriptor

Derived AJCC M

Derived AJCC M Descriptor

Derived AJCC Stage Group

Derived SS1977

Derived SS2000

Figure 1 illustrates the relationship between the input items and the derived output items. All output items are assigned a "storage value" which is stored in the computer and used for data transmission and analysis, and an associated "display value" which is displayed on the computer screen or in printed reports. The display values (for example, "N3c") were designed to be familiar and readily interpretable to registrars and physicians.

## Schematic Diagram of Relationships of Inputs and Outputs for Collaborative Staging

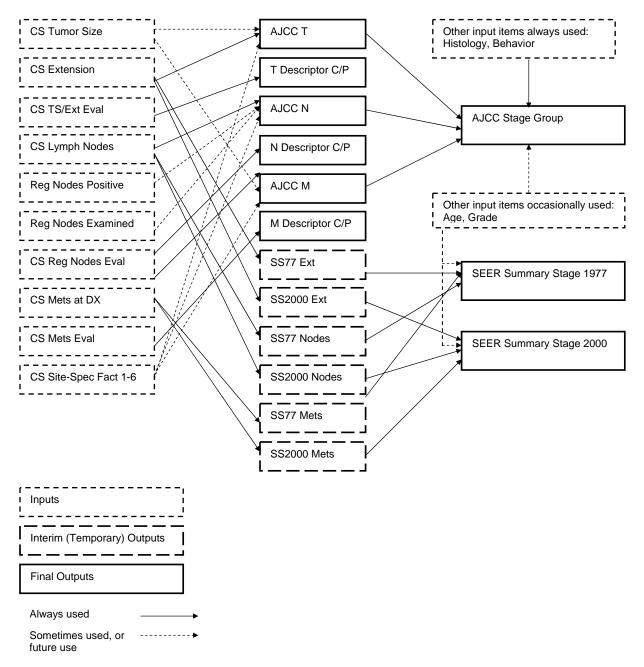


Figure 1. Relationships of inputs and outputs for CS. Collaborative Staging Task Force of the American Joint Committee on Cancer. *Collaborative Staging Manual and Coding Instructions*, Version 1.0. Jointly published by American Joint Committee on Cancer (Chicago, IL) and U.S. Department of Health and Human Services (Bethesda, MD), 2003.

## **Timing of Data Collection**

The data collected in the Collaborative Staging System are limited to information gathered through completion of surgery(ies) in the first course of treatment, OR all information available within four months of the date of diagnosis in the absence of disease progression, whichever is *longer*.

Disease progression is defined as further direct extension or distant metastasis known to have developed after the diagnosis was established. Information about tumor extension, lymph node involvement, or distant metastasis obtained after disease progression is documented should be excluded from the CS coding.

# **Coding CS Items**

- a. Code the CS items for every analytic case. Read the medical record carefully to identify the primary site and histology and determine their ICD-O-3 codes. While you are reviewing the record, make mental notes about the tissues and lymph nodes that are involved by tumor.
- b. Chose the appropriate schema from Part II of the CS Manual for instructions and codes.
  - (1) If the histology is melanoma (8720-8790), Kaposi sarcoma (9140), retinoblastoma (9510-9514), lymphoma (9590-9699 and 9702-9729), mycosis fungoides (9700-9701), or hematopoietic and reticuloendothelial system (9731-9989), use the histology-specific schema for the appropriate histology-site combination.
  - (2) Otherwise, use the applicable site-specific schema. Schemas are in ICD-O-3 order by the first code that uses the schema. Verify that you are in the correct chapter by confirming that the code is in the list at the beginning of the schema.
- c. Begin assigning codes for the 15 Collaborative Staging data items. Be sure to read the notes and follow the site/histology-specific instructions at the beginning of each item. Some schemas may have site-specific factors associated with extension, lymph nodes, or metastasis. Keep these in mind as you assign the codes.
  - Code the tumor size in the CS Tumor Size item.
  - Code the extent of direct tumor spread in the CS Extension item.
  - Code how the farthest direct tumor spread was determined in the CS Tumor Size/Ext Eval item.
  - Code whether regional lymph nodes are involved in the CS Lymph Nodes items.
  - Code how the farthest regional lymph node spread was determined in the CS Reg Node Eval item.
  - Code the number of positive regional lymph nodes from the pathology report in the Regional Nodes Positive item.
  - Code the number of regional lymph nodes examined by the pathologist in the Regional Nodes Examined item.
  - Code the farthest distant metastasis (including distant lymph nodes) in the CS Mets at Dx item.
  - Code how the distant metastasis was determined in the CS Mets Eval item.
  - Code the six CS Site-Specific Factors. If the first site-specific factor is listed as "Not applicable," code 888 in all site-specific factors. Otherwise, code the specific information requested for each site-specific factor. When the next site-specific factor is 888 (Not Applicable), all the remaining site-specific factors will also be 888.
- d. When all the CS codes are completed, the computer can convert them into the T, N, M, Stage Group, Summary Stage 1977, and Summary Stage 2000. Depending on your software system, the final stage information may be derived now, when the case is saved, or prior to exiting the case. When the computer derives the final stage information, the program will check the histology code and other coded information to determine whether T, N, M and Stage Group will be generated for the case. If the histology code is on the computer's exceptions list for that site, the T, N, M, and Stage Group will be reported as "Not applicable." Summary Stage is generated for every case.

# **Site-Specific Factors**

Some schemas require prognostic information not required for most sites. *CS Site-Specific Factors 1-6* are designed to collect that information. The schemas that make use of one or more site-specific factors are:

- Head and neck\*
- Stomach
- Colon
- Rectosigmoid, rectum
- Liver
- Malignant melanoma of skin, vulva, penis, scrotum
- Mycosis fungoides
- Breast
- Ovary
- Placenta
- Prostate
- Testis
- Malignant melanoma of conjunctiva
- Malignant melanoma of iris and ciliary body
- Malignant melanoma of other eye
- Brain
- Thyroid
- Kaposi sarcoma
- Hodgkin lymphoma and non-Hodgkin lymphoma
  - \* Head and neck includes the following schemas: upper lip; lower lip; other lip; base of tongue; anterior tongue; upper gum; lower gum and retromolar trigone; other gum; floor of mouth; hard palate; soft palate/uvula; other mouth; buccal mucosa; parotid gland; submandibular gland; other salivary glands; oropharynx; anterior surface of epiglottis; nasopharynx; pyriform sinus/hypopharynx; other pharynx; nasal cavity; middle ear; maxillary sinus; ethmoid sinus; other sinus; glottic larynx; supraglottic larynx; subglottic larynx; other larynx

#### **Using CS Derived Values**

The implementation of Collaborative Staging does <u>not</u> affect CoC requirements for physicians to assign AJCC staging or the requirement that the physician-assigned staging values be recorded in the registry.

Some differences in the way that the CS algorithm operates and how the AJCC stage assignment rules are written can result in valid discrepancies between the derived values and the physician-assigned staging. Such differences are explained below.

- 1) The AJCC Cancer Staging Manual distinguishes between clinical and pathologic staging components and has specific rules governing how the components may be combined. The CS algorithm derives a clinical or pathologic descriptor for each of the T, N, and M components but uses the components to derive a stage group without reference to the value of the descriptors. Consequently, the CS algorithm may assign a Derived AJCC Stage Group value based on combinations that are neither clinical nor pathologic according to AJCC rules and are therefore unstageable under AJCC rules. Other Derived AJCC Stage Group values may involve combinations that do not match either the physician-assigned AJCC clinical staging or the pathologic staging.
- 2) The CS algorithm has a built-in set of histologies to which each site-specific CS schema applies when it derives AJCC stage and component values. That list is not as strictly defined by AJCC with respect to most sites. Consequently, it is possible a physician will provide an AJCC stage for a patient when the CS algorithm does not.

## 42A. CS TUMOR SIZE

Item Length: 3
Data Type: Numeric
ACoS: Required\*
State Registry: Require

State Registry: Required\*

\*For cases diagnosed 01/01/2004 and later.

## Description

This item records the largest dimension or diameter of the **primary tumor**, and is always recorded in millimeters.

#### Rationale

Tumor size at diagnosis is an independent prognostic indicator for many tumors and it is used by Collaborative Staging to derive some AJCC "T" codes.

#### Codes

Code	Description
000	Indicates no mass or no tumor found; e.g., when a tumor of a stated primary site is not found, but the tumor has metastasized.
001-988	Exact size in millimeters
989	989 millimeters or larger
990	Microscopic focus or foci only; no size of focus is given
991	Described as less than 1 cm
992	Described as less than 2 cm
993	Described as less than 3 cm
994	Described as less than 4 cm
995	Described as less than 5 cm
	Site-Specific Codes Where Needed
999	Unknown; size not stated; not stated in patient record

## Instructions

- a. Refer to site/histology-specific instructions in the *Collaborative Staging Manual and Coding Instructions*, Version 01.04.00 (CS Manual) for additional information.
- b. Code the exact size of the primary tumor in millimeters (mm) for all sites/histologies except those for which it is stated to be not applicable.

## Conversion/Rounding

To convert centimeters to millimeters, move the decimal point one digit to the right (or multiply the centimeters by 10).

0.1cm = 1 mm 1 cm = 10 mm 3.2 cm = 32 mm

- If tumor size is given in tenths of millimeters, round down if .5 mm or less, and round up for .6 through .9 mm. (Record 999 if 0.5 mm or less.)
- Formulas for converting inches to millimeters are listed below.

394 inch = 10 mm1 inch = 25 mm

- c. Record tumor size from documentation in the following priority order:
  - Record tumor size from the pathology report, if available, when the patient receives no radiation or systemic treatment prior to surgery.

- Record the largest tumor size documented, whether prior to or following treatment, if the patient receives preoperative (neoadjuvant) systemic therapy (chemotherapy, hormone therapy, immunotherapy) or radiation therapy.
- Record the tumor size documented from imaging/radiographic techniques when there is no more specific size information from a pathology or operative report. Record the largest size reported if there is a difference in reported tumor size among imaging and radiographic techniques.
- d. Record the largest dimension or diameter of tumor, whether it is from an excisional biopsy specimen or the complete resection of the primary tumor.

# e. Invasive and In Situ Components

- 1) If both an in situ and an invasive component are present, and the invasive component is measured, record the size of the invasive component even if it is smaller.
- 2) For breast primaries: If the size of the invasive component is not given, record the size of the entire tumor from the surgical report, pathology report, radiology report, or clinical examination.
- 3) For purely in situ lesions, code the size as stated.
- f. Always code the size of the primary tumor, not the size of the polyp, ulcer, cyst, or distant metastasis. (However, if the tumor is described as a "cystic mass" and only the size of the entire mass is given, code the size of the entire mass, since the cysts are part of the tumor itself.)
- g. Do not add pieces or chips together to create a whole. However, if the pathologist states an aggregate or composite size (determined by fitting the tumor pieces together and measuring the total size), record that size.
- h. Record tumor size (lateral dimension or diameter) for malignant melanoma. (Code depth of invasion in *Site-Specific Factor 1*.)
- i. Use code 999 for the following:
  - If no size is given;
  - If size is 0.5 mm or less;
  - For an incisional needle biopsy. (In the rare event that a needle biopsy removes an entire tumor, record the tumor size.)
- j. Microscopic residual tumor does not affect overall tumor size.

# k. Special Codes

Record **998** when the following terms describe tumor involvement in the sites listed below. (The descriptions below take precedence over any mention of size.)

<ul> <li>Esophagus (C15.0 – C15.9)</li> <li>Stomach (C16.0 – C16.9)</li> <li>Colorectal (C18.0 – C20.9)</li> </ul>	Entire circumference Diffuse; widespread; 3/4 or more; linitis plastica Familial/multiple polyposis (histology 8220 or 8221 with a behavior code of /2 or /3)
<ul> <li>Lung and main stem bronchus (C34.0 – C34.9)</li> </ul>	Diffuse, entire lobe or lung
■ Breast (C50.0 – C50.9)	Diffuse; widespread; 3/4 or more of breast; inflammatory carcinoma

Record 990 when no gross tumor is seen and tumor is only identified microscopically.

The terms microscopic focus, microfocus, and microinvasion are not the same as [macroscopic] focal or focus. A macroscopic focus or foci indicates a very small or isolated area, pinpoint, or spot of tumor that may be visible grossly. Only tumor identified microscopically should be coded 990.

Codes **991** through **995** are non-specific size descriptions that, for some sites, are used to determine a "T" category. If a specific size is given, code the more precise size in the range of 001-989.

Record 888 for the following diagnoses and/or primary sites where size is not applicable:

- Hematopoietic, reticuloendothelial, immunoproliferative, myelodysplastic or myeloproliferative neoplasms (9731-9734, 9740-9742, 9750-9758, 9760-9762, 9764-9769, 9800-9801, 9805, 9820, 9823, 9826-9827, 9831-9837, 9840, 9860-9861, 9863, 9866-9867, 9870-9876, 9891, 9895-9897, 9910, 9920, 9930-9931, 9940, 9945-9946, 9948, 9950, 9960-9964, 9970, 9975, 9980, 9982-9987, 9989);
- Hodgkin and non-Hodgkin lymphoma (9590-9729 except 9700/3 and 9701/3);
- Unknown or ill-defined primary sites (C76.0-C76.5, C76.7-C76.8, C80.9) and C42.\_ and C77.\_ other than hematopoietic, reticuloendothelial, immunoproliferative, myeloproliferative, and myelodysplastic neoplasms as listed above, Hodgkin and non-Hodgkin lymphomas as listed above, and Kaposi sarcoma 9140/3.
- I. See the individual site/histology schemas for further information and definitions.

## Codes with Examples:

- 001 Prostate needle biopsy shows 0.6 mm carcinoma (round up six-tenths of mm).
- 008 Thyroidectomy specimen with 8 mm carcinoma.
- 014 Tumor is mixed in situ and invasive adenocarcinoma, total 3.7 cm in size, of which 1.4 cm is invasive.
- 019 Duct carcinoma in situ covering a 1.9 cm area with focal areas of invasive ductal carcinoma.
- O22 Patient has a 2.2 cm mass in the oropharynx. Fine needle aspiration of mass confirms squamous cell carcinoma. Patient receives course of neoadjuvant combination chemotherapy. Pathologic size of tumor after total resection is 0.8 cm.
- 023 Infiltrating duct carcinoma with extensive in situ component. Total size is 2.3 cm.
- O28 Chest x-ray shows 3.5 cm mass. The pathology report from the surgery states that the same mass is malignant and measures 2.8 cm.
- 033 A 3.3 cm tumor is 33 millimeters.
- 040 CT of chest shows 4 cm mass in RUL.
- D51 Tumor is described as 2.4 x 5.1 x 1.8 cm in size.
- 990 Cervix conization: severe dysplasia with focal areas of microinvasion. Code tumor size as microscopic focus, no size given.
- 999 Ovary specimen: extensive cystic disease with focal areas of tumor seeding. Disregard "focal" and code tumor size to unknown.

## 42B. CS EXTENSION

Item Length: 2
Data Type: Numeric
ACoS: Required\*

State Registry: Required\*

\*For cases diagnosed 01/01/2004 and later.

# **Description**

This item identifies contiguous growth (extension) of the primary tumor within the organ of origin or its direct extension into neighboring organs. For certain sites such as ovary, discontinuous metastasis is coded in *CS Extension*. See site-specific schemas for detailed codes and coding instructions.

#### Rationale

Tumor extension at diagnosis is a prognostic indicator used by Collaborative Staging to derive some AJCC "T" codes and some SEER Summary Stage codes.

## Codes

Code	Description	TNM Mapping	SS77 Mapping	SS2000 Mapping
00	In situ; non-invasive	Tis	IS	IS
	Site/Histology-Specific Codes With the exception of corpus uteri and ovary, all codes represent contiguous (direct) extension of tumor from the site of origin to the organ/structure /tissue represented in the code.			
80	Further contiguous extension			
95	No evidence of primary tumor	T0	U	U
99	Unknown extension; primary tumor cannot be assessed; not stated in patient record	TX	U	U

- a. Refer to site/histology-specific instructions in the *Collaborative Staging Manual and Coding Instructions*, Version 01.04.00 (CS Manual) for additional information.
- b. Code the farthest documented extension of the primary tumor. Do not include discontinuous metastases to distant sites that are coded in *CS Mets at Dx* except for ovary and corpus uteri.
- c. Record tumor size from documentation in the following priority order:
  - Record extension from the pathology report, if available, when the patient receives no radiation or systemic treatment prior to surgery.
  - Record the farthest extension documented, whether identified clinically prior to treatment or pathologically following treatment, if the patient receives preoperative (neoadjuvant) systemic therapy (chemotherapy, hormone therapy, immunotherapy) or radiation therapy.
  - Record the extent of disease documented from imaging/radiographic techniques when there is no more specific size information from a pathology or operative report.
- d. Refer to the Ambiguous Terminology section of the *CS Manual* for terms that constitute tumor involvement or extension.
- e. If an involved organ or tissue is not mentioned in the schema, approximate the location and code by comparing it with listed organs or tissues in the same anatomic area.
- f. If the information in the medical record is ambiguous or incomplete regarding the extent to which the tumor has spread, the extent of disease may be inferred from the physician's statement of a "T" category of the AJCC staging system or a stage from a site-specific staging system, such as Dukes' C. Record the numerically lowest equivalent extension code for the "T" category.

- g. Do not code *CS Extension* as "in situ" if there is any evidence of nodal or metastatic involvement. Use the code for "Localized, NOS" if there is no better information.
- h. Some site or histology schemas include designations such as T1, NOS; T2, NOS; Localized, NOS; and other non-specific categories. The NOS is added when there is further breakdown of the category into subsets (such as T1a, T1b, T1c), but the correct subset cannot be determined. The NOS designation, which can appear in both the descriptions of codes and the mapping, is not official AJCC descriptive terminology. The NOS should be disregarded in reports and analyses when it is not a useful distinction. The data collector should only code to a category such as "Stated as T1 NOS" when the appropriate subset (e.g., T1a or T1b) cannot be determined.
- The presence of microscopic residual disease or positive tumor margins does not increase the extension code.

## **CS TUMOR SIZE/EXT EVAL**

Item Length: 1
Data Type: Numeric
ACoS: Required

State Registry: Required\*

\*Required for cases diagnosed 01/01/2008 and later.

# Description

This item records how the codes for the two items *CS Tumor Size* and *CS Extension* were determined, based on the diagnostic methods employed.

#### Rationale

This item is used by Collaborative Staging to describe whether the staging basis for the AJCC "T" code is clinical or pathologic and to record applicable prefix and suffix descriptors used with AJCC staging.

## Codes

Code	Description	Staging Basis
0	No surgical resection done. Evaluation based on physical examination, imaging examination, or other non-invasive clinical evidence. No autopsy evidence used.	С
1	No surgical resection done. Evaluation based on endoscopic examination, diagnostic biopsy (including fine needle aspiration biopsy), or other invasive techniques. No autopsy evidence used.	C*
	Does not meet criteria for AJCC pathologic staging.	
2	No surgical resection done, but evidence derived from autopsy (tumor was suspected or diagnosed prior to autopsy).	p
3	Surgical resection performed <b>without</b> pre-surgical systemic treatment or radiation; <b>OR</b> surgical resection performed, unknown if pre-surgical systemic treatment or radiation performed.	p
	Meets criteria for AJCC pathologic staging.	
	Evaluation based on evidence acquired before treatment, supplemented or modified by the additional evidence acquired during and from surgery, particularly from pathologic examination of the resected specimen.	
5	Surgical resection performed <b>with</b> pre-surgical systemic treatment or radiation; tumor size/extension based on clinical evidence.	С
6	Surgical resection performed <b>with</b> pre-surgical systemic treatment or radiation; <b>but</b> tumor size/extension based on pathologic evidence.	у
8	Evidence from autopsy only (tumor was unsuspected or undiagnosed prior to autopsy).	а
9	Unknown if surgical resection done. Not assessed; cannot be assessed. Unknown if assessed. Not documented in patient record.	С
	For sites with no AJCC schema; not applicable.	

<sup>\*</sup> For some primary sites, code 1 may be a pathologic staging basis.

- a. Refer to site/histology-specific instructions in the *Collaborative Staging Manual and Coding Instructions*, Version 01.04.00 (CS Manual) for additional information.
- b. Select the code that documents the report or procedure from which the information about the farthest extension or size of the primary tumor was obtained (the information that results in the highest "T" category). This may not be the numerically highest eval code.
  - Code 0, 1, or 9 if the patient had no surgery.
     Exception: Lung cancer with mediastinoscopy showing direct extension into mediastinum. Use code 1. Staging algorithm will identify information as pathologic (p) because mediastinoscopy is defined as a pathologic procedure in AJCC staging.

- Code 3 or 9 if the patient had surgery followed by other treatment(s).
- Code 3 or 6 if the size or extension of the tumor was greater after treatment than before treatment.
- Code 5 or 6 if the size or extension of the tumor determined prior to treatment was the basis for neoadjuvant therapy.
- Code 2 if the patient had an autopsy and the diagnosis was known or suspected prior to death.
- Code 8 if the patient had an autopsy and the malignancy was not known or suspected prior to death.
- c. For primary sites/histologies where tumor size is not a factor in determining the "T" category in AJCC (see Table 5 in General Instructions of the CS Manual), code this data item on the basis of CS Extension only.
- d. For primary sites where both tumor size and extension determine the "T" category in AJCC (see Table 4 in the General Instructions), select the code that best explains how the information in the CS Tumor Size and CS Extension data items were determined.

If there is a difference between the derived category for the tumor size and the CS extension, select the evaluation code that reflects how the worse or higher category was determined.

- e. For sites/histologies where there is no AJCC schema, this data item may be coded 9, "Not applicable." (See Table 6 in General Instructions of the *CS Manual*.)
- f. Code 0 includes imaging studies such as standard radiography, special radiographic projections, tomography, computerized tomography (CT), ultrasonography, lymphography, angiography, scintigraphy (nuclear scans), ultrasonography, magnetic resonance imaging (MRI), positron emission tomography (PET) scans, spiral scanning (CT or MRI), and other non-invasive methods of examining tissues.
- g. Code 1 generally includes microscopic analysis of tissue insufficient to meet the requirements for pathologic staging in the AJCC system. Pathologic staging requirements vary by site. For some site schemas, code 1 may be classified as pathologic. For specific classification rules, refer to the AJCC Cancer Staging Manual, Sixth Edition.

Code 1 also includes observations at surgery, such as an exploratory laparotomy in which unresectable pancreatic cancer is identified, where further tumor extension is not biopsied. Use code 3 for a biopsy of tumor extension that meets the requirements for pathologic staging basis. That is, if the biopsy documents the highest "T" category, the biopsy meets the requirements for pathologic staging basis and CS Tumor Size/Ext Eval should be coded 3.

#### Codes with Examples:

- Tumor size for a breast cancer biopsy is 020 (maps to T1). There is ulceration of the skin (extension code 50, maps to T4). Use code 0; the evaluation is based on physical examination and the ulceration information from the physical examination results in a higher "T" category.
- O Patient has a chest x-ray showing an isolated 4 cm tumor in the right upper lobe. Patient opts for radiation therapy. Use code 0. Staging algorithm would identify information as clinical (c).
- 1 Fine needle aspiration biopsy (eval code 2) confirms adenocarcinoma of prostate. CT scan of pelvis (eval code 1) shows tumor extension through the prostatic capsule into adjacent connective tissues. Use code 1 since the CT scan showed more extensive tumor than the biopsy.
- 1 Colon cancer with colonoscopy and biopsy confirming cancer. Use code 1. Staging algorithm would identify information as clinical (c). The biopsy does not meet the criteria for pathologic staging.
- 1 Endoscopies for cervix or bladder. Use code 1. The staging algorithm would identify the information as clinical (c).

## 42C. CS LYMPH NODES

Item Length: 2
Data Type: Numeric
ACoS: Required\*

State Registry: Required\*

\*For cases diagnosed 01/01/2004 and later.

# Description

This item identifies the regional lymph nodes involved with cancer at the time of diagnosis.

## Rationale

The involvement of specific regional lymph nodes is a prognostic indicator used by Collaborative Staging to derive some AJCC "N" codes and SEER Summary Stage codes.

#### Codes

Code	Description	TNM Mapping	SS77 Mapping	SS2000 Mapping
00	None; no regional lymph node involvement	N0	None	None
	Site/Histology-Specific Codes			
80	Lymph nodes, NOS	NX	RN	RN
90	Unknown; regional lymph nodes cannot be assessed; not stated in patient record	NX	U	U

#### Instructions

- a. Refer to site/histology-specific instructions in the *Collaborative Staging Manual and Coding Instructions*, Version 01.04.00 (CS Manual) for additional information.
- b. Record the specific regional lymph node chain farthest from the primary site that is involved by tumor either clinically or pathologically.

Regional lymph nodes are listed for each site/histology. In general, the regional lymph nodes in the chain closest to the primary site have the lower codes. Nodes farther away from the primary or in farther lymph node chains have higher codes. Record the highest applicable code.

**Exception:** The higher codes for "Regional lymph nodes, NOS;" "Lymph nodes, NOS;" "Stated as N1, no other information;" "Stated as N2a, no other information," and so forth, should only be used when there is no available information as to the name(s) of the regional nodes involved.

- c. Record involved regional lymph nodes from the pathology report, if it is available, when the patient receives no radiation or systemic treatment prior to surgery.
- d. If there is a discrepancy between clinical information and pathologic information about the same lymph nodes, the pathologic information takes precedence unless the patient received preoperative therapy. If the patient received preoperative (neoadjuvant) systemic therapy (chemotherapy, hormone therapy, immunotherapy) or radiation therapy, the clinical status of the lymph nodes takes precedence.
- e. Code 00 for lymph node involvement when the *CS Extension* is coded in situ, even if no lymph nodes are removed, since "in situ" by definition means non-invasive.
- f. If there is direct extension of the primary tumor into a regional lymph node, record the involved node in this data item.
- g. Terms Considered Involvement of Lymph Nodes
  - For solid tumors: "Fixed," "matted," or "mass" in the hilum, mediastinum, retroperitoneum, and/or

mesentery" (with no specific information as to tissue involved) are considered

involvement of lymph nodes.

• For lymphomas: Any mention of lymph nodes is indicative of involvement.

- For lung primaries: "Adenopathy," "enlargement," or "mass" in the hilum or mediastinum is considered involvement of lymph nodes.
- h. Terms Not Considered Involvement of Lymph Nodes
  Terms such as "palpable," "enlarged," "visible swelling," "shotty," or "lymphadenopathy" should be
  ignored unless there is a statement of involvement by the clinician. (Exceptions for lung are identified
  under paragraph g above.)
- i. For inaccessible sites, primarily for localized or early stage (T1, T2) cancers:

  Record regional lymph nodes as negative rather than unknown (based on clinical evaluation) when there is no mention of regional lymph node involvement in the physical examination, pre-treatment diagnostic testing, or surgical exploration and the patient receives what would be usual treatment to the primary site. (See the CS Manual for further discussion.)
- j. Any unidentified nodes included with the resected primary site specimen are to be coded as "Regional lymph nodes, NOS."
- k. If the information in the medical record is ambiguous or incomplete regarding the extent to which the tumor has spread, lymph node involvement may be inferred from the physician's statement of an "N" category of the AJCC staging system or a stage from a site-specific staging system, such as Dukes' C. Record the numerically lowest CS Lymph Nodes code for that "N" category.
  - If there is a discrepancy between documentation in the medical record and the physician's assignment of TNM, the documentation takes precedence. Cases of this type should be discussed with the physician who assigned the TNM.
- I. When size of involved regional lymph nodes is required, code from the pathology report, if available. Code the size of the metastasis, not the entire node, unless otherwise stated in site-specific schemas. The size of the metastasis within the lymph node can be inferred if the size for the entire node falls within one of the codes. For example, a single involved node 1.5 cm in size can be coded to "Single lymph node ≤ 2 cm" because the metastasis cannot be larger than 1.5 cm.
- m. Some site or histology schemas include designations such as N1, NOS; N2, NOS; and other non-specific categories. The NOS is added when there is further breakdown of the category into subsets (such as N1a, N1b, N1c), but the correct subset cannot be determined. The NOS designation, which can appear in both the descriptions of codes and the mapping, is not official AJCC descriptive terminology. The NOS should be disregarded in reports and analyses when it is not a useful distinction. The data collector should only code to a category such as "Stated as N1, NOS" when the appropriate subset (e.g., N1a or N1b) cannot be determined.
- n. The terms "homolateral," "ipsilateral," and "same side" are used interchangeably.

# Codes with Examples:

- 00 Axillary lymphadenopathy stated as "suspicious for involvement" noted on physical exam. After axillary dissection, all lymph nodes are negative. Use code 00.
- 10 Patient has needle biopsy-proven prostate cancer with no mention of involved lymph nodes on physical examination (Negative, code 00). He receives Lupron while deciding whether to undergo a radical prostatectomy. At the time of surgery, a laparoscopic pelvic node biopsy is reported to show metastases (Regional nodes involved, code 10) to lymph nodes and the prostatectomy is canceled. Use code 10 because the preoperative treatment (Lupron) had no effect on the lymph nodes.
- 50 Patient has a hard matted mass in the axilla (code 50) and a needle biopsy of the breast that confirms ductal carcinoma. Patient receives three months of chemotherapy. The pathology report from the modified radical mastectomy shows only scar tissue in the axilla with no involvement of axillary lymph nodes (Negative, code 00). Use code 50 because the chemotherapy apparently "sterilized" the lymph nodes.

# CS REG NODES EVAL Item Length: 1 Data Type: Numeric ACoS: Required\* State Registry: Optional

\*For cases diagnosed 01/01/2004 and later.

# **Description**

This item records how the code for CS Lymph Nodes was determined, based on the diagnostic methods employed.

#### Rationale

This data item is used by Collaborative Staging to describe whether the staging basis for the AJCC "N" code is clinical or pathologic and to record applicable prefix and suffix descriptors used with AJCC staging.

## Codes

Code	Description	Staging Basis
0	No regional lymph nodes removed for examination. Evaluation based on physical examination, imaging examination, or other non-invasive clinical evidence. No autopsy evidence used.	С
1	No regional lymph nodes removed for examination. Evaluation based on endoscopic examination, diagnostic biopsy (including fine needle lymph node aspiration), or other invasive techniques. No autopsy evidence used.	С
	Does not meet criteria for AJCC pathologic staging.	
2	No regional lymph nodes removed for examination, but evidence derived from autopsy (tumor was suspected or diagnosed prior to autopsy).	р
3	Regional lymph nodes removed for examination (removal of at least 1 lymph node) without pre-surgical systemic treatment or radiation; <b>OR</b> lymph nodes removed for examination, unknown if pre-surgical systemic treatment or radiation performed.	р
	Meets criteria for AJCC pathologic staging.	
5	Regional lymph nodes removed for examination <b>with</b> pre-surgical systemic treatment or radiation, and lymph node evaluation based on clinical evidence.	С
6	Regional lymph nodes removed for examination <b>with</b> pre-surgical systemic treatment or radiation, <b>but</b> lymph node evaluation based on pathologic evidence.	У
8	Evidence from autopsy only (tumor was unsuspected or undiagnosed prior to autopsy).	а
9	Unknown if lymph nodes removed for examination. Not assessed; cannot be assessed. Unknown if assessed. Not documented in patient record. For sites that have no AJCC staging; not applicable.	С

- a. Refer to site/histology-specific instructions in the *Collaborative Staging Manual and Coding Instructions*, Version 01.04.00 (CS Manual) for additional information.
- b. Select the code that best explains how the information for *CS Lymph Nodes* was determined. Select the code that documents the report or procedure from which the information about the farthest involved regional lymph nodes was obtained. This may not be the numerically highest eval code.
  - Code 0, 1, or 9 if the patient had no removal of lymph node(s).
  - Code 3 or 9 if the patient had removal of lymph node(s) followed by other treatment(s).
  - Code 3 if the lymph node procedure meets the requirements for the pathologic staging basis of regional lymph nodes.
  - Code 3 or 6 if the size, number, or extension of regional lymph node involvement was greater after treatment than before treatment.

- Code 5 or 6 if the size, number, or extension of regional lymph node involvement determined prior to treatment was the basis for neoadjuvant therapy.
- Code 2 if the patient had an autopsy and the diagnosis was known or suspected prior to death.
- Code 8 if the patient had an autopsy and the malignancy was not known or suspected prior to death.
- c. Code 0 includes imaging studies such as standard radiography, special radiographic projections, tomography, computerized tomography (CT), ultrasonography, lymphography, angiography, scintigraphy (nuclear scans), ultrasonography, magnetic resonance imaging (MRI), positron emission tomography (PET) scans, spiral scanning (CT or MRI), and other non-invasive methods of examining tissues.
- d. Code 1 includes microscopic analysis of tissue insufficient to meet the requirements for pathologic staging in the AJCC system.
  - Code 1 also includes observations at surgery, such as abdominal exploration at the time of a colon resection, where regional lymph nodes are not biopsied.
- e. Code 9 may be used for this data item for sites/histologies where there is no AJCC schema (see Table 5 in General Instructions of the CS Manual).

## Codes with Examples:

- 0 Modified radical neck dissection for hypopharyngeal cancer shows one lower jugular node involved (CSReg LN code 10, eval code 3). Physical exam shows hard, matted scalene (transverse cervical) node presumed to contain metastasis (CS Reg LN code 32, eval code 0). Code this data item 0 since the scalene node involvement was determined clinically rather than by examination of tissue.
- 1 Lung cancer with CT scan or MRI showing involved contralateral mediastinal nodes. Code this data item 1. Staging algorithm would identify information as clinical (c).
- Prostate cancer with laparoscopic lymph node biopsy showing involved nodes. Radical prostatectomy was canceled. Code this data item 3. Staging algorithm would identify information as pathologic (p). A positive biopsy of one or more regional lymph nodes is sufficient to meet the pathologic staging basis for prostate cancer.

## 42D. CS METS AT DX

Item Length: 2
Data Type: Numeric
ACoS: Required\*
State Registry: Required\*

\*For cases diagnosed 01/01/2004 and later.

# Description

This item identifies the distant site(s) of metastatic involvement at time of diagnosis. This data item represents distant metastases (The AJCC "M" component or distant stage in Summary Staging) at the time of diagnosis. In other words, when the patient was diagnosed, tumor had already spread indirectly (through vascular or lymph channels) to a site remote from the primary tumor.

The structure of this data item is based on the "M" category of AJCC. In some schemas, there may be additional items in *CS Extension* or *CS Lymph Nodes* that map to distant stage in Summary Staging (77 and/or 2000) and there may be some items in *CS Mets at Dx* that map to regional stage in Summary Staging. Regardless of where such items are recorded, the staging algorithms will properly account for the information.

#### Rationale

The presence of metastatic disease at diagnosis is an independent prognostic indicator, and it is used by Collaborative Staging to derive AJCC "M" codes and SEER Summary Stage codes.

## Codes

Code	Description	TNM Mapping	SS77 Mapping	SS2000 Mapping
00	No; none	MO	None	None
10	Distant lymph nodes(s)	M1	D	D
40	Distant metastasis except code 10 Distant metastasis, NOS Carcinomatosis	M1	D	D
	Site/Histology-Specific Codes Where Needed			
50	(40) + (10)	M1	D	D
99	Unknown; distant metastasis cannot be assessed; not stated in patient record	MX	U	U

- a. Refer to site/histology-specific instructions in the *Collaborative Staging Manual and Coding Instructions*. Version 01.04.00 (CS Manual) for additional information.
- b. Assign the highest applicable code for metastasis at diagnosis, whether the determination was clinical or pathologic and whether or not the patient had any preoperative systemic therapy.
- c. Do not record metastasis known to have developed after the extent of disease was established (also referred to as progression of disease) in this data item.
- d. Use code 00, rather than code 99, when the clinician proceeds with standard treatment of the primary site for localized or early (T1, T2) stage, since this action presumes that there are no distant metastasis that would otherwise alter the treatment approach. Code 99 can and should be used in situations where there is reasonable doubt that the tumor is no longer localized and there is no documentation of distant metastasis.
- e. If the only indication of extension in the record is the physician's statement of an "M" category from the AJCC staging system or a stage from a site-specific staging system, such as Dukes' D, record the numerically lowest equivalent extension code for that "M" category. In most cases, this will be 40, "Distant metastasis, NOS."

CS METS EVAL	Item Length: 1
	Data Type: Numeric
	ACoS: Required*
	State Registry: Optional

\*For cases diagnosed 01/01/2004 and later.

# **Description**

This item records how the code for *CS Mets at Dx* was determined, based on the diagnostic methods employed.

#### Rationale

This data item is used by Collaborative Staging to describe whether the staging basis for the AJCC "M" code is clinical or pathologic and to record applicable prefix and suffix descriptors used with AJCC staging.

# Codes

Code	Description	Staging Basis
0	No pathologic examination of metastatic tissue performed. Evaluation of distant metastasis based on physical examination, imaging examination, and/or other non-invasive clinical evidence. No autopsy evidence used.	С
1	No pathologic examination of metastatic tissue performed. Evaluation of distant metastasis based on endoscopic examination or other invasive techniques. No autopsy evidence used.	С
	Does not meet criteria for AJCC pathologic staging of distant metastasis.	
2	No pathologic examination of metastatic tissue done prior to death, but evidence derived from autopsy (tumor was suspected or diagnosed prior to autopsy).	р
3	Pathologic examination of metastatic tissue performed <b>without</b> pre-surgical systemic treatment or radiation; <b>OR</b> pathologic examination of metastatic tissue performed, unknown if pre-surgical systemic treatment or radiation performed.	р
	Meets criteria for AJCC pathologic staging of distant metastasis.	
5	Pathologic examination of metastatic tissue performed <b>with</b> pre-surgical systemic treatment or radiation, and metastasis based on clinical evidence.	С
6	Pathologic examination of metastatic tissue performed <b>with</b> pre-surgical systemic treatment or radiation, <b>but</b> metastasis based on pathologic evidence.	У
8	Evidence from autopsy only (tumor was unsuspected or undiagnosed prior to autopsy).	а
9	Not assessed; cannot be assessed. Unknown if assessed. Not documented in patient record. For sites that have no AJCC staging; not applicable.	С

- a. Refer to site/histology-specific instructions in the *Collaborative Staging Manual and Coding Instructions*, Version 01.04.00 (CS Manual) for additional information.
- b. Select the *CS Mets Eval* code that best explains how the information in *CS Mets at Dx* was determined. Select the code that documents the method of evaluation for metastatic involvement farthest from the primary site. This may not be the numerically highest eval code.
  - Code 0, 1, or 9 if the patient had no examination of metastatic tissue.
  - Code 3 if the patient had removal of presumed metastatic tissue (even though the pathology report was negative).
  - Code 3 if the diagnosis of distant metastasis meets the requirements for the pathologic staging basis.
  - Code 6 if biopsies taken after pre-operative treatment are negative for metastasis and clinical evidence of metastasis remains.

- Code 2 if the patient had an autopsy and the diagnosis was known or suspected prior to death.
- Code 8 if metastasis at diagnosis was identified at autopsy and the malignancy was not known or suspected prior to death.
- c. Code 0 includes imaging studies such as standard radiography, special radiographic projections, tomography, computerized tomography (CT), ultrasonography, lymphography, angiography, scintigraphy (nuclear scans), ultrasonography, magnetic resonance imaging (MRI), positron emission tomography (PET) scan, spiral scanning (CT or MRI), and other non-invasive methods of examining tissues.
- d. Code 1 includes microscopic analysis of tissue insufficient to meet the requirements for pathologic staging in the AJCC system.
  - Code 1 also includes observations at surgery, such as abdominal exploration at the time of a colon resection, where distant metastasis is not biopsied.
- e. Code 9 may be used for primary sites/histologies where here is no AJCC schema (See Table 4 of the CS Manual.

## Codes with Examples:

- 0 Liver palpated and reported as normal during laparotomy for stomach cancer (eval code 1). CT scan of brain shows multiple metastatic nodules (eval code 0). Code this data item 0. The brain would be reported as involved but the liver would not be reported as involved.
- O Patient has diagnosis of colon cancer by biopsy. CT scan shows liver metastasis. Code this data item 0. Staging algorithm will indicate information is clinical (c).
- O Colon cancer patient has CT scan showing normal lungs. During the resection, the surgeon palpates the liver and finds it to be normal. Code this data item 0, since the CT scan shows that potential metastatic sites outside the surgical field are negative.
- 1 Lung cancer with endoscopy of contralateral lung showing involvement of contralateral mainstem bronchus. Code this data item 1. Staging algorithm will indicate information is clinical (c).
- 3 Prostate cancer with enlarged scalene node confirmed as cancer on needle biopsy. Code this data item 3. Staging algorithm will indicate information is pathologic (p), since the biopsy of the metastatic site confirms M1 disease.

## 42E. CS SITE-SPECIFIC FACTOR 1

Item Length: 3
Data Type: Numeric
ACoS: Required\*

State Registry: Required\*

Item updated for CS Version 01.04.00.

\*For cases diagnosed 01/01/2004 and later.

# Description

This item identifies information that is necessary to derive tumor (T), lymph node (N), metastasis (M), or AJCC stage group, or is considered to be of clinical or prognostic importance.

#### Rationale

Site-specific factors are used to record additional staging information needed by Collaborative Staging to derive AJCC TNM and/or SEER Summary Stage codes for specified site-histology schemas.

#### Codes

Code	Description
000	None
	Site/Histology-Specific Codes
888	Not applicable for this site; schema does not use this site-specific factor
999	Unknown; [site-specific title] cannot be assessed; not documented in patient record

#### Instructions

- a. Refer to site/histology-specific instructions in the *Collaborative Staging Manual and Coding Instructions*, Version 01.04.00 (CS Manual) for additional information.
- b. The following primary sites/histologies use *Site-Specific Factor 1* to code information. See the site-specific schemas for acceptable codes and their definitions.

Head and neck* Stomach Colon Rectosigmoid, rectum Liver Malignant melanoma of skin, vulva, penis, scrotum Mycosis fungoides Breast Ovary Placenta Prostate Size of lymph nodes Clinical assessment of regional lymph nodes Carcinoembryonic antigen (CEA) Carcinoembryonic antigen (CEA) Alpha-fetoprotein (AFP) Measured thickness (depth), Breslow's measurement Peripheral blood involvement Estrogen receptor assay (ERA) Carbohydrate antigen 125 (CA-125) Prognostic scoring index Prostate-specific antigen (PSA) lab value
Colon Rectosigmoid, rectum Liver Malignant melanoma of skin, vulva, penis, scrotum Mycosis fungoides Breast Ovary Placenta  Carcinoembryonic antigen (CEA) Carcinoembryonic antigen (CEA) Malpha-fetoprotein (AFP) Measured thickness (depth), Breslow's measurement Peripheral blood involvement Estrogen receptor assay (ERA) Carbohydrate antigen 125 (CA-125) Prognostic scoring index
Rectosigmoid, rectum Liver Malignant melanoma of skin, vulva, penis, scrotum Mycosis fungoides Breast Ovary Placenta  Carcinoembryonic antigen (CEA) Alpha-fetoprotein (AFP) Measured thickness (depth), Breslow's measurement Peripheral blood involvement Estrogen receptor assay (ERA) Carbohydrate antigen 125 (CA-125) Prognostic scoring index
Liver Malignant melanoma of skin, vulva, penis, scrotum Mycosis fungoides Breast Ovary Placenta  Alpha-fetoprotein (AFP) Measured thickness (depth), Breslow's measurement Peripheral blood involvement Estrogen receptor assay (ERA) Carbohydrate antigen 125 (CA-125) Prognostic scoring index
Malignant melanoma of skin, vulva, penis, scrotum Mycosis fungoides Breast Ovary Placenta  Measured thickness (depth), Breslow's measurement Peripheral blood involvement Estrogen receptor assay (ERA) Carbohydrate antigen 125 (CA-125) Prognostic scoring index
Mycosis fungoides  Breast  Ovary  Peripheral blood involvement  Estrogen receptor assay (ERA)  Carbohydrate antigen 125 (CA-125)  Prognostic scoring index
Breast Estrogen receptor assay (ERA) Ovary Carbohydrate antigen 125 (CA-125) Placenta Prognostic scoring index
Ovary Carbohydrate antigen 125 (CA-125) Placenta Prognostic scoring index
Placenta Prognostic scoring index
Prostate Prostate-specific antigen (PSA) lab value
Testis Alpha-fetoprotein (AFP)
Malignant melanoma of conjunctiva Measured thickness (depth), Breslow's measurement
Malignant melanoma of iris and ciliary body CS Extension Iris
Malignant melanoma of choroid Measured thickness (depth), Breslow's measurement
Malignant melanoma of other eye Measured thickness (depth), Breslow's measurement
Brain WHO histologic grade
Thyroid Solitary vs. multifocal
Kaposi sarcoma Associated with HIV/AIDS
Hodgkin lymphoma and non-Hodgkin lymphoma Associated with HIV/AIDS

\*Refer to "Overview of Collaborative Staging" in this chapter for a list of head and neck schemas.

- c. Code 000 when there is a statement in the record that a test was not performed.
- d. Code 888 if there is no site/histology-specific factor for a schema.
- e. Code 999 if there is no report of a lab test in the patient record.
- Code 999 (Unknown), rather than 002 (Not present), for Kaposi sarcoma if AIDS status is not documented.

## 42F. CS SITE-SPECIFIC FACTOR 2

Item Length: 3
Data Type: Numeric
ACoS: Required\*
State Registry: Required\*

Item updated for CS Version 01.04.00.

\*For cases diagnosed 01/01/2004 and later.

# Description

This item identifies information that is necessary to derive tumor (T), lymph node (N), metastasis (M), or AJCC stage group, or is considered to be of clinical or prognostic importance.

#### Rationale

Site-specific factors are used to record additional staging information needed by Collaborative Staging to derive AJCC TNM and/or SEER Summary Stage codes for specified site-histology schemas.

## Codes

Code	Description
000	None
	Site/Histology-Specific Codes
888	Not applicable for this site; schema does not use this site-specific factor
999	Unknown; [site-specific title] cannot be assessed; not documented in patient record

- a. Refer to site/histology-specific instructions in the *Collaborative Staging Manual and Coding Instructions*, Version 01.04.00 (CS Manual) for additional information.
- b. The following primary sites/histologies use *Site-Specific Factor 2* to code information. See the site-specific schemas for acceptable codes and their definitions.

<u>Site/Histology</u>	<u>Factor</u>
Head and neck*	Extracapsular extension, lymph nodes for head and neck
Colon	Clinical assessment of regional lymph nodes
Rectosigmoid, rectum	Clinical assessment of regional lymph nodes
Liver	Fibrosis score
Malignant melanoma of skin, vulva, penis, scrotum	Ulceration
Breast	Progesterone receptor assay (PRA)
Prostate	Prostate-specific antigen (PSA) (interpretation)
Testis	Human chorionic gonadotropin (HCG)
Malignant melanoma of iris and ciliary body	CS extension of ciliary body
Hodgkin lymphoma and non-Hodgkin lymphoma	Systemic symptoms at diagnosis

<sup>\*</sup>Refer to "Overview of Collaborative Staging" in this chapter for a list of head and neck schemas.

- c. Code 000 when there is a statement in the record that a test was not performed.
- d. Code 888 if there is no site/histology-specific factor for a schema.
- e. Code 999 if there is no report of a lab test in the patient record.
- Code 000 for malignant melanoma of skin if ulceration is not mentioned in the pathology report.

## 42G. CS SITE-SPECIFIC FACTOR 3

Item Length: 3
Data Type: Numeric
ACoS: Required\*

State Registry: Required\*

\*For cases diagnosed 01/01/2004 and later.

# **Description**

This item identifies information that is necessary to derive tumor (T), lymph node (N), metastasis (M), or AJCC stage group, or is considered to be of clinical or prognostic importance.

#### Rationale

Site-specific factors are used to record additional staging information needed by Collaborative Staging to derive AJCC TNM and/or SEER Summary Stage codes for specified site-histology schemas.

#### Codes

Code	Description	
000	None	
	Site/Histology-Specific Codes	
888	Not applicable for this site; schema does not use this site-specific factor	
999	Unknown; [site-specific title] cannot be assessed; not documented in patient record	

## Instructions

- a. Refer to site/histology-specific instructions in the *Collaborative Staging Manual and Coding Instructions*, Version 01.04.00 (CS Manual) for additional information.
- b. The following primary sites/histologies use *Site-Specific Factor 3* to code information. See the site-specific schemas for acceptable codes and their definitions.

Site/Histology	<u>Factor</u>
Head and neck*	Levels I-III, lymph nodes for head and neck
Malignant melanoma of skin, vulva, penis, scrotum	Clinical status of lymph node mets
Breast	Number of positive ipsilateral axillary lymph nodes
Prostate	CS extension – pathologic extension
Testis	Lactate dehydrogenase (LDH)
Hodgkin lymphoma and non-Hodgkin lymphoma	International Prognostic Index (IPI) Score

\*Refer to "Overview of Collaborative Staging" in this chapter for a list of head and neck schemas.

- c. Code 000 when there is a statement in the record that a test was not performed.
- d. Code 888 if there is no site/histology-specific factor for a schema.
- e. Code 999 if there is no report of a lab test in the patient record.
- f. Code 999 for lymphomas if the IPI score is not stated in the record. It is not necessary to calculate the IPI score from other information in the record.

## **CS SITE-SPECIFIC FACTOR 4**

Item Length: 3
Data Type: Numeric
ACoS: Required\*
State Registry: Optional

\*For cases diagnosed 01/01/2004 and later.

## Description

This item identifies information that is necessary to derive tumor (T), lymph node (N), metastasis (M), or AJCC stage group, or is considered to be of clinical or prognostic importance.

#### Rationale

Site-specific factors are used to record additional staging information needed by Collaborative Staging to derive AJCC TNM and/or SEER Summary Stage codes for specified site-histology schemas.

# Codes

Code	Description	
000	None	
	Site/Histology-Specific Codes	
888	Not applicable for this site; schema does not use this site-specific factor	
999	Unknown; [site-specific title] cannot be assessed; not documented in patient record	

- a. Refer to site/histology-specific instructions in the *Collaborative Staging Manual and Coding Instructions*, Version 01.04.00 (CS Manual) for additional information.
- b. The following primary sites/histologies use *Site-Specific Factor 4* to code information. See the site-specific schemas for acceptable codes and their definitions.

Site/Histology	<u>Factor</u>
Head and neck*	Levels IV-V and retropharyngeal lymph nodes for head
	and neck
Malignant melanoma of skin, vulva, penis, scrotum	Lactate dehydrogenase (LDH)
Breast	Immunohistochemistry (IHC) of regional lymph nodes
Prostate	Prostatic acid phosphatase (PAP)
Testis	Radical orchiectomy performed

<sup>\*</sup>Refer to "Overview of Collaborative Staging" in this chapter for a list of head and neck schemas.

- c. Code 000 when there is a statement in the record that a test was not performed.
- d. Code 888 if there is no site/histology-specific factor for a schema.
- e. Code 999 if there is no report of a lab test in the patient record.

	Itana I an other 2
CS SITE-SPECIFIC FACTOR 5	Item Length: 3 Data Type: Numeric ACoS: Required*
	State Registry: Optional

\*For cases diagnosed 01/01/2004 and later.

# **Description**

This item identifies information that is necessary to derive tumor (T), lymph node (N), metastasis (M), or AJCC stage group, or is considered to be of clinical or prognostic importance.

#### Rationale

Site-specific factors are used to record additional staging information needed by Collaborative Staging to derive AJCC TNM and/or SEER Summary Stage codes for specified site-histology schemas.

## Codes

Code	Description	
000	None	
	Site/Histology-Specific Codes	
888	Not applicable for this site; schema does not use this site-specific factor	
999	Unknown; [site-specific title] cannot be assessed; not documented in patient record	

- a. Refer to site/histology-specific instructions in the *Collaborative Staging Manual and Coding Instructions*, Version 01.04.00 (CS Manual) for additional information.
- b. The following primary sites/histologies use *Site-Specific Factor 5* to code information. See the site-specific schemas for acceptable codes and their definitions.

Site/Histology	<u>Factor</u>
Head and neck*	Levels VI-VII and facial lymph nodes for head and
	neck
Breast	Molecular studies of regional lymph nodes
Prostate	Gleason primary pattern and secondary pattern value
Testis	Size of metastasis in lymph nodes

<sup>\*</sup>Refer to "Overview of Collaborative Staging" in this chapter for a list of head and neck schemas.

- c. Code 000 when there is a statement in the record that a test was not performed.
- d. Code 888 if there is no site/histology-specific factor for a schema.
- e. Code 999 if there is no report of a lab test in the patient record.

	Harris Landin O
CS SITE-SPECIFIC FACTOR 6	Item Length: 3 Data Type: Numeric
	ACoS: Required*
	State Registry: Optional

\*For cases diagnosed 01/01/2004 and later.

# Description

This item identifies information that is necessary to derive tumor (T), lymph node (N), metastasis (M), or AJCC stage group, or is considered to be of clinical or prognostic importance.

#### Rationale

Site-specific factors are used to record additional staging information needed by Collaborative Staging to derive AJCC TNM and/or SEER Summary Stage codes for specified site-histology schemas.

## Codes

Code	Description	
000	None	
	Site/Histology-Specific Codes	
888	Not applicable for this site; schema does not use this site-specific factor	
999	Unknown; [site-specific title] cannot be assessed; not documented in patient record	

- a. Refer to site/histology-specific instructions in the *Collaborative Staging Manual and Coding Instructions*, Version 01.04.00 (CS Manual) for additional information.
- b. The following primary sites/histologies use *Site-Specific Factor 6* to code information. See the site-specific schemas for acceptable codes and their definitions.

Site/Histology Head and neck*	Factor
neau anu neck	Parapharyngeal, parotid, preauricular, and sub- occipital lymph nodes, lymph nodes for head and neck
Breast	Size of tumor – invasive component
Prostate	Gleason score

<sup>\*</sup>Refer to "Overview of Collaborative Staging" in this chapter for a list of head and neck schemas.

- c. Code 000 when there is a statement in the record that a test was not performed.
- d. Code 888 if there is no site/histology-specific factor for a schema.
- e. Code 999 if there is no report of a lab test in the patient record.

## **DERIVED AJCC T**

Item Length: 2
Data Type: Numeric
ACoS: Autocoded\*

State Registry: Autocoded\*

\*For cases diagnosed 01/01/2004 and later.

## Description

This item is the AJCC "T" staging element derived from coded fields using the CS algorithm.

#### Rationale

Collaborative Staging (CS) was developed to provide a single uniform set of codes and rules for coding the elements necessary to derive "best stage" for the major staging systems in current use. Derived AJCC T can be used to evaluate disease spread at diagnosis, plan and track treatment patterns, and analyze outcomes.

- a. This data item is autocoded and is not recorded by registry staff.
- b. The two-digit storage codes are designed for analytic purposes.
- c. The display string is the corresponding label that is displayed on the screen or in reports. The meaning of these display strings will be clear to the registrar or physician user.
- d. Refer to the applicable AJCC Cancer Staging Manual "T" descriptions.

T Storage Code	Display String
99	TX
90	T0
01	Та
05	Tis
06	Tispu
07	Tispd
10	T1
11	T1mic
19	T1NOS
12	T1a
13	T1a1
14	T1a2
15	T1b
16	T1b1
17	T1b2
18	T1c
20	T2

T Storage Code	Display String	
29	T2NOS	
21	T2a	
22	T2b	
23	T2c	
30	T3	
39	T3NOS	
31	T3a	
32	T3b	
33	T3c	
40	T4	
49	T4NOS	
41	T4a	
42	T4b	
43	T4c	
44	T4d	
88	NA	

## **DERIVED AJCC T DESCRIPTOR**

Item Length: 1
Data Type:

ACoS: Autocoded\*

State Registry: Autocoded\*

\*For cases diagnosed 01/01/2004 and later.

## Description

This item is the AJCC "T Descriptor" derived from coded fields using the CS algorithm.

#### Rationale

Collaborative Staging (CS) was developed to provide a single uniform set of codes and rules for coding the elements necessary to derive "best stage" for the major staging systems in current use. Derived AJCC T Descriptor can be used in analysis to differentiate the timing of staging with respect to the treatment process.

- a. This data item is autocoded and is not recorded by registry staff.
- b. For those cases in which classification is performed during or following initial multimodality therapy, the category is identified by a "y prefix" to be derived from the computerized algorithm.
- c. Refer to the applicable AJCC Cancer Staging Manual for prefix definitions.

Code	Description
С	Clinical stage
р	Pathologic stage
а	Autopsy stage
у	Surgical resection performed <b>after</b> pre-surgical systemic treatment or radiation; tumor size/extension based on pathologic evidence.

## **DERIVED AJCC N**

Item Length: 2
Data Type: Numeric
ACoS: Autocoded\*

State Registry: Autocoded\*

\*For cases diagnosed 01/01/2004 and later.

## Description

This item is the AJCC "N" staging element derived from coded fields using the CS algorithm.

#### Rationale

Collaborative Staging (CS) was developed to provide a single uniform set of codes and rules for coding the elements necessary to derive "best stage" for the major staging systems in current use. Derived AJCC N can be used to evaluate disease spread at diagnosis, plan and track treatment patterns, and analyze outcomes.

- a. This data item is autocoded and is not recorded by registry staff.
- b. The two-digit storage codes are designed for analytic purposes.
- c. The display string is the corresponding label that is displayed on the screen or in reports. The meaning of these display strings will be clear to the registrar or physician user.
- d. Refer to the applicable AJCC Cancer Staging Manual "N" descriptions.

N Storage Code	Display String	
99	NX	
00	N0	
09	N0NOS	
01	N0(i-)	
02	N0(i+)	
03	N0(mol-)	
04	N0(mol+)	
10	N1	
19	N1NOS	
11	N1a	
12	N1b	
13	N1c	

N Storage Code	Display String	
18	N1mi	
20	N2	
29	N2NOS	
21	N2a	
22	N2b	
23	N2c	
30	N3	
39	N3NOS	
31	N3a	
32	N3b	
33	N3c	
88	NA	

## **DERIVED AJCC N DESCRIPTOR**

Item Length: 1
Data Type:

ACoS: Autocoded\*

State Registry: Autocoded\*

\*For cases diagnosed 01/01/2004 and later.

## Description

This item is the AJCC "N Descriptor" derived from coded fields using the CS algorithm.

#### Rationale

Collaborative Staging (CS) was developed to provide a single uniform set of codes and rules for coding the elements necessary to derive "best stage" for the major staging systems in current use. Derived AJCC N Descriptor can be used in analysis to differentiate the timing of staging with respect to the treatment process.

- a. This data item is autocoded and is not recorded by registry staff.
- b. For those cases in which classification is performed during or following initial multimodality therapy, the category is identified by a "y prefix" to be derived from the computerized algorithm.
- c. Refer to the applicable AJCC Cancer Staging Manual for prefix definitions.

Code	Description
С	Clinical stage
р	Pathologic stage
а	Autopsy stage
у	Lymph nodes removed for examination <b>after</b> pre-surgical systemic treatment or radiation and lymph node evaluation based on pathologic evidence.

## **DERIVED AJCC M**

Item Length: 2 Data Type: Numeric ACoS: Autocoded\*

State Registry: Autocoded\*

\*For cases diagnosed 01/01/2004 and later.

## Description

This item is the AJCC "M" staging element derived from coded fields using the CS algorithm.

#### Rationale

Collaborative Staging (CS) was developed to provide a single uniform set of codes and rules for coding the elements necessary to derive "best stage" for the major staging systems in current use. Derived AJCC M can be used to evaluate disease spread at diagnosis, plan and track treatment patterns, and analyze outcomes.

- a. This data item is autocoded and is not recorded by registry staff.
- b. The two-digit storage codes are designed for analytic purposes.
- c. The display string is the corresponding label that is displayed on the screen or in reports. The meaning of these display strings will be clear to the registrar or physician user.
- d. Refer to the applicable AJCC Cancer Staging Manual "M" descriptions.

M Storage Code	Display String	
99	Mx	
00	MO	
10	M1	
11	M1a	
12	M1b	
13	M1c	
19	M1NOS	
88	NA	

## **DERIVED AJCC M DESCRIPTOR**

Item Length: 1
Data Type:

ACoS: Autocoded\*

State Registry: Autocoded\*

\*For cases diagnosed 01/01/2004 and later.

## Description

This item is the AJCC "M Descriptor" derived from coded fields using the CS algorithm.

#### Rationale

Collaborative Staging (CS) was developed to provide a single uniform set of codes and rules for coding the elements necessary to derive "best stage" for the major staging systems in current use. Derived AJCC M Descriptor can be used in analysis to differentiate the timing of staging with respect to the treatment process.

- a. This data item is autocoded and is not recorded by registry staff.
- b. For those cases in which classification is performed during or following initial multimodality therapy, the category is identified by a "y prefix" to be derived from the computerized algorithm.
- c. Refer to the applicable AJCC Cancer Staging Manual for prefix definitions.

Code	Description
С	Clinical stage
р	Pathologic stage
а	Autopsy stage
у	Pathologic examination of metastatic tissue <b>after</b> pre-surgical systemic treatment or radiation and extension based on pathologic evidence.

## **DERIVED AJCC STAGE GROUP**

Item Length: 2
Data Type: Numeric
ACoS: Autocoded\*

State Registry: Autocoded\*

\*For cases diagnosed 01/01/2004 and later.

## Description

This item is the AJCC "Stage Group" derived using the CS algorithm.

#### Rationale

Collaborative Staging (CS) was developed to provide a single uniform set of codes and rules for coding the elements necessary to derive "best stage" for the major staging systems in current use. Derived AJCC Stage Group can be used to evaluate patterns of disease spread at diagnosis, track treatment patterns, and analyze outcomes.

- a. This data item is autocoded and is not recorded by registry staff.
- b. The two-digit storage codes are designed for analytic purposes.
- c. The display string is the corresponding label that is displayed on the screen or in reports. The meaning of these display strings will be clear to the registrar or physician user.
- d. Refer to the applicable AJCC Cancer Staging Manual "Stage Group" descriptions.

T Storage Code	Display String	
00	0	
01	0a	
02	0is	
10		
11	INOS	
12	IA	
13	IA1	
14	IA2	
15	IB	
16	IB1	
17	IB2	
18	IC	
19	IS	
23	ISA	
24	ISB	
20	IEA	
21	IEB	
22	IE	
30	II	
31	IINOS	
32	IIA	
33	IIB	
34	IIC	
35	IIEA	
36	IIEB	
37	IIE	
38	IISA	

T Storage Code Display String		
39	IISB	
40	IIS	
41	IIESA	
42	IIESB	
43	IIES	
50	III	
51	IIINOS	
52	IIIA	
53	IIIB	
54	IIIC	
55	IIIEA	
56	IIIEB	
57	IIIE	
58	IIISA	
59	IIISB	
60	IIIS	
61	IIIESA	
62	IIIESB	
63	IIIES	
70	IV	
71	IVNOS	
72	IVA	
73	IVB	
74	IVC	
88	NA	
90	OCCULT	
99	UNK	

# **DERIVED SS1977**

Item Length: 1
Data Type: Numeric
ACoS: Autocoded\*

State Registry: Autocoded\*

\*For cases diagnosed 01/01/2004 and later.

# Description

This item is the "SEER Summary Stage 1977" derived using the CS algorithm.

## Rationale

Collaborative Staging (CS) was developed to provide a single uniform set of codes and rules for coding the elements necessary to derive "best stage" for the major staging systems in current use. Derived SS1977 can be used to evaluate patterns of disease spread at diagnosis, track treatment patterns, and analyze outcomes.

# Instructions

Refer to the SEER Summary Staging Manual, 1977 for site-specific categories.

Code	Description
0	In situ
1	Localized
2	Regional, direct extension only
3	Regional, regional lymph nodes only
4	Regional, direct extension and regional lymph nodes
5	Regional, NOS
7	Distant metastases/systemic disease
9	Unstaged, unknown, or unspecified
(leave blank)	Not derived

# **DERIVED SS2000**

Item Length: 1
Data Type: Numeric
ACoS: Autocoded\*

State Registry: Autocoded\*

\*For cases diagnosed 01/01/2004 and later.

## Description

This item is the "SEER Summary Stage 2000" derived using the CS algorithm.

## Rationale

Collaborative Staging (CS) was developed to provide a single uniform set of codes and rules for coding the elements necessary to derive "best stage" for the major staging systems in current use. Derived SS2000 can be used to evaluate disease spread at diagnosis, plan and track treatment patterns, and analyze outcomes.

# Instructions

Refer to the SEER Summary Staging Manual, 2000 for site-specific categories.

Code	Description
0	In situ
1	Localized
2	Regional, direct extension only
3	Regional, regional lymph nodes only
4	Regional, direct extension and regional lymph nodes
5	Regional, NOS
7	Distant metastases/systemic disease
9	Unstaged, unknown, or unspecified
(leave blank)	Not derived

#### 43. SUBSTANTIATE STAGING RMCDS Item: Staging

Data Type: Text ACoS: N/A

State Registry: Required

# Description

This is a required text field in the paper and RMCDS abstracts for recording a narrative description of information that substantiates the Summary Stage or the Collaborative Staging (CS) data items, as applicable. It is not sufficient to merely code the items. The information from the medical record supporting the codes must be recorded. Facilities using other types of registry software should follow their vendor's instructions for recording text that substantiates staging.

#### Instructions

a. Identify the specific evidence in the medical record that justifies the staging and record the evidence briefly, in this field. Standard abbreviations can be used to save space. It is not necessary to repeat information documented in other text fields.

## Examples:

Staging Text

Summary Stage 4 Small cell carcinoma of the rt. lung with extension to the pericardium

and mets to 3 of 4 hilar lymph nodes.

Summary Stage 1 Poorly differentiated adenocarcinoma of the sigmoid colon with

invasion through the muscularis propria. LN neg.

Summary Stage 7 Mucinous cystadenocarcinoma of the rt. ovary with extension to the

small intestine.

Diffuse, histiocytic malignant lymphoma of the cervical and Summary Stage 5

mediastinal lymph node regions. Bone marrow free of disease.

CS Tumor Size: 005 5 mm melanoma, 1.2 mm thick, no ulceration, 20 neg. LN,

CS Extension: 30 remainder of physical exam negative

CS Lymph Nodes: 00 CS Reg LN Pos: 00 CS Reg LN Exam: 20 CS Mets at DX: 00

CS Site-specific Factor 1: 120

CS Site-specific Factor 2: 000

- b. Use this field to clarify any coding that is vague (e.g., specific metastatic site coded as a "9") or to justify any coding that requires the coder to override an edit error message (e.g., metastatic site coding that is consistent with AJCC staging but inconsistent with Summary Stage).
- c. Document any unresolved discrepancies between physician and registry staging decisions.
- d. Facilities using the paper abstract to report should also attach copies of medical record documentation (such as the pathology and operative reports) that substantiates the extent of disease. However, text that substantiates the staging must be completed by all reporting facilities.

#### **GENERAL RULES FOR TNM STAGING**

The fields for TNM (Tumor, Nodes, Metastasis) staging are optional for hospitals to complete. Hospitals are strongly encouraged to complete TNM coding because it may be a future requirement for JCAHO accreditation and third party reimbursement. Instructions follow for hospitals that wish to complete the TNM items. If you elect <u>not</u> to complete these optional items, skip to page 177 for Treatment Data instructions.

## **ACoS Requirements**

Hospitals with cancer programs approved by the American College of Surgeons (ACoS) must record pathologic or clinical classifications of TNM and stage group in order to meet ACoS approval standards.

In October 1981, the Commission on Cancer resolved that the staging system of the American Joint Committee on Cancer (AJCC) would be used in all approved cancer programs. The AJCC developed its staging system for evaluating trends in the treatment and control of cancer. This staging is used by physicians to estimate prognosis, plan treatment, evaluate new types of therapy, analyze outcome, design follow-up strategies, and assess early detection results.

In 1982, breast cancer was the first site implemented. Effective January 1991, ACoS required AJCC TNM staging for all required (analytic) cases that had a staging scheme in the *AJCC Manual for Staging of Cancer*, Third Edition. The Commission has since published the fourth, fifth, and sixth editions of the manual. The effective dates for the various editions are listed below.

AJCC Second Edition: Effective for cases diagnosed in 1988 or earlier.

AJCC **Third Edition:** Effective for cases diagnosed from 1989 through 1992. AJCC **Fourth Edition:** Effective for cases diagnosed from 1993 through 1997. AJCC **Sixth Edition:** Effective for cases diagnosed from 1998 through 2002. Effective for cases diagnosed in 2003 and later.

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Beginning in 1995, the Commission on Cancer required that the clinical and pathologic T, N, and M components be recorded by the managing or treating physician, rather than the cancer registrar. This change was implemented to improve the quality of staging information and to enhance the accuracy of outcome data.

#### **AJCC Staging System**

The TNM system for describing the anatomic extent of disease is based on the assessment of three components:

T = The extent of the primary **tumor** 

N = The absence or presence and extent of regional lymph **node** metastasis

M = The absence or presence of **distant metastasis** 

The TNM elements are defined for specific sites in the *AJCC Cancer Staging Manual*. These elements should be recorded on a staging form or in the medical record. Although the TNM elements must be assigned by the physician in ACoS approved programs, it is recommended that the registrar continue to independently stage each case when abstracting to ensure data reliability.

Because the AJCC staging system does not include all sites, ACoS approved programs must code Summary Stage 2000 (Item 42) for cancers with no AJCC staging schema. Appendix H lists which sites do not have AJCC site-specific staging schemes.

Refer to the *AJCC Cancer Staging Manual* and review Chapter 1, "Purposes and Principles of Staging" and the rules in each of the site-specific chapters. Each site-specific chapter outlines the site(s) and histologies that are included in the chapter.

## **Definitions**

- a. Clinical classification is based on information and evidence obtained before treatment. Use it for sites that are accessible for clinical examination including cervix, oral cavity, and larynx. Use clinical classification for organs where only clinical findings evaluate the extent of disease. The physical examination, imaging, endoscopy, biopsy, surgical exploration, and other relevant findings are the basis of clinical staging. Evaluate the clinical stage of disease using all information available before the first cancer-directed treatment. The clinical stage is essential to select and evaluate therapy.
- b. Pathologic classification is based on information obtained before treatment and supplemented by additional evidence from surgery and pathologic examination of the resected specimen. It is a combination of all findings. The pathologic stage provides the most precise data to estimate prognosis and calculate end results. Pathologic assessment of the primary tumor requires a resection of the primary tumor or a biopsy adequate to evaluate the highest pT (pathologic Tumor) category. The pathologic assessment of the regional lymph nodes requires the removal of enough nodes to confirm the absence of regional lymph node metastasis and evaluate the highest pN (pathologic Nodes) category.

## Rule

Pathologic staging takes precedence over clinical staging.

**Exception:** There are some diseases and sites for which clinical staging takes precedence. Clinical staging takes precedence when the patient has radiation or chemotherapy preoperatively and when the patient does not have cancer-directed surgery.

Example 1: Cervical cancer treated pre-operatively with radiation.

Example 2: Breast cancer treated pre-operatively with chemotherapy and radiation.

Example 3: Prostate cancer biopsied and treated with hormones.

Example 4: Small cell carcinoma of the lung biopsied and treated with chemotherapy.

Example 5: Pancreas primary diagnosed without histologic confirmation.

## **General Instructions**

- a. Locate the specific site in the AJCC manual for the assignment of TNM elements.
- b. When AJCC staging does not apply to a particular site or histology because they have been excluded from the *AJCC Cancer Staging Manual*, record 88 in the T, N, M, and Stage Group fields.
- c. When the primary site is unknown, staging may be based on clinical suspicion of the site of origin. If no suspected site of origin is identified, record 88 in the T, N, M, and Stage Group fields.

44.	CLINICAL T	Item Length: 2 Data Type: Alphanumeric Left Justified, Blank Fill ACoS: Required State Registry: Optional
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## Description

This is an optional 2-character field to record a code for the clinical T classification. The clinical T evaluates only the primary tumor and reflects tumor size and/or extension.

#### **Definitions**

- a. Clinical T classification is based on information and evidence obtained before treatment. Use it for sites that are accessible for clinical examination including cervix, oral cavity, and larynx. Use clinical classification for organs where only clinical findings evaluate the extent of disease. The physical examination, imaging, endoscopy, biopsy, surgical exploration, and other relevant findings are the basis of clinical staging. Evaluate the clinical stage of disease using all information available before the first cancer-directed treatment. The clinical stage is essential to select and evaluate therapy.
- b. The following general definitions are used throughout the TNM classification:
  - TX Primary tumor cannot be assessed or is unknown
  - TO No evidence of a primary tumor
  - Tis Carcinoma in situ
  - T1, T2, T3, and T4 describe increasing size and/or local extent of the primary tumor

## Codes

X =	TX	2 =	T2
0 =	T0	2A =	T2a
A =	Ta	2B =	T2b
IS =	Tis	2C =	T2c
SU =	Tis pu	3 =	Т3
SD =	Tis pd	3A =	Т3а
1M =	T1mic	3B =	T3b
1 =	1	3C =	T3c
1A =	T1a	4 =	T4
A1 =	T1a1	4A =	T4a
A2 =	T1a2	4B =	T4b
1B =	T1b	4C =	T4c
B1 =	T1b1	4D =	T4d
B2 =	T1b2	88 =	Not applicable (no AJCC staging scheme)
1C =	T1c		,

- a. Enter the T (Tumor) code for the primary tumor. This item is a one or two digit code. If the code is only one digit, enter it in the first space (left justify) and leave the second space blank. Truncate the least significant subdivision of the category from the right as needed. (See example under Nodes section.)
- b. Choose the lower (less advanced) T category when there is any uncertainty. Refer to the *AJCC Cancer Staging Manual* for coding rules.
- c. Tumor size is necessary to classify T for several sites.
- d. Record 88 when the site or histologic type does not have an AJCC staging scheme.

- Examples: Leukemia, lymphoma, dermatofibrosarcoma, etc. The pathology report identifies a breast mass as sarcoma. The breast staging scheme in the AJCC Cancer Staging Manual applies only to carcinomas. Record T88.
- e. Record X when the site or histologic type has an AJCC staging scheme but there is not enough information to assign a T value.

Example: A patient has a fine-needle biopsy of a breast mass. The cytology identifies infiltrating ductal carcinoma. The patient is lost to follow-up. AJCC staging requires tumor size and palpation of axillary lymph nodes for clinical staging. Record TX NX MX.

45.	CLINICAL N	Item Length: 2 Data Type: Alphanumeric Left Justified, Blank Fill ACoS: Required State Registry: Optional
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## Description

This is an optional 2-character field to record a code for the clinical N classification. The clinical N identifies the absence or presence of regional lymph node metastases and describes the extent of regional lymph node metastases.

#### **Definitions**

The following general definitions are used throughout the TNM classification:

NX Regional lymph nodes cannot be assessed or status is unknown.

NO Nodes were assessed and there was no evidence of regional lymph node metastasis.

N1, N2, and N3 indicate increasing involvement of regional lymph nodes.

#### Codes

X =	NX	2B =	N2b
0 =	N0	2C =	N2c
1 =	N1	3 =	N3
1A =	N1a	3A =	N3a
1B =	N1b	3B =	N3b
2 =	N2	3C =	N3c
2A =	N2a	88 =	Not applicable (no AJCC staging scheme)

## Instructions

a. Enter the N (Nodes) code with the appropriate suffix for regional lymph node involvement that describes the absence of involvement or increasing degrees of involvement. This item is a one or two digit code. If the code is only one digit, enter it in the first space (left justify) and leave the second space blank. Truncate the least significant subdivision of the category from the right as needed.

Example: N1biii is entered as 1B. The N is omitted and the iii is truncated (cut off) from the right, since only 2 digits can be entered.

- b. Choose the lower (less advanced) N category when there is any uncertainty. Refer to the *AJCC Cancer Staging Manual* for coding rules.
- c. Record 88 when the site or histologic type does not have an AJCC staging scheme.
  - Examples: Leukemia, lymphoma, dermatofibrosarcoma, etc. The pathology report identifies a breast mass as sarcoma. The breast staging scheme in the AJCC Cancer Staging Manual applies only to carcinomas. Record N88.
- d. Record X when the site or histologic type has an AJCC staging scheme but there is not enough information to assign an N value.

Example: A patient has a fine-needle biopsy of a breast mass. The cytology identifies infiltrating ductal carcinoma. The patient is lost to follow-up. AJCC staging requires tumor size and palpation of axillary lymph nodes for clinical staging. Record TX NX MX.

# 46. CLINICAL M Item Length: 2 Data Type: Alphanumeric Left Justified, Blank Fill ACoS: Required State Registry: Optional

#### Description

This is an optional 2-character field to record a code for the clinical M classification. The clinical M records the presence or absence of distant metastases.

#### **Definitions**

The following general definitions are used throughout the TNM classification:

MX The presence of distant metastasis cannot be assessed or is unknown

M0 No known distant metastasis

M1 Distant metastases are present

#### Codes

X = MX

0 = M0

1 = M1

1A = M1a

1B = M1b

1C = M1c

88 = Not applicable (no AJCC staging scheme)

#### Instructions

- a. Enter the M (Metastasis) code for the presence or absence of distant metastasis. This item is a one or two digit code. If the code is only one digit, enter it in the first space (left justify) and leave the second space blank. Truncate the least significant subdivision of the category from the right as needed.
- b. Choose the lower (less advanced) M category when there is any uncertainty. Refer to the *AJCC Cancer Staging Manual* for coding rules.
- c. Record 88 when the site or histologic type does not have an AJCC staging scheme.
  - Examples: Leukemia, lymphoma, dermatofibrosarcoma, etc. The pathology report identifies a breast mass as sarcoma. The breast staging scheme in the AJCC Cancer Staging Manual applies only to carcinomas. Record M88.
- d. Record X when the site or histologic type has an AJCC staging scheme but there is not enough information to assign an M value.
  - Example: A patient has a fine-needle biopsy of a breast mass. The cytology identifies infiltrating ductal carcinoma. The patient is lost to follow-up. AJCC staging requires tumor size and palpation of axillary lymph nodes for clinical staging. Record TX NX MX.
- e. When a patient with multiple primaries develops metastases, a biopsy may distinguish the source of distant disease. Stage both primaries as having metastatic disease if the physician is unable to conclude which primary has metastasized. If the physician later identifies which primary has metastasized, update the stage(s) as appropriate.

# 47. CLINICAL STAGE GROUP Item Length: 2 Data Type: Alphanumeric Left Justified, Blank Fill ACoS: Required State Registry: Optional

#### Description

This is an optional 2-character field for recording a code that condenses the clinical T, N, and M elements into categories for purposes of tabulation and analysis. It defines the anatomic extent of disease based on the previously coded T, N, and M elements. The information should be reported if you are already collecting it, e.g., if your hospital has a cancer program approved by the American College of Surgeons, Commission on Cancer.

The TNM (Tumor, Nodes, Metastasis) Stage Grouping codes are from the *AJCC Cancer Staging Manual*. Efforts should be made to capture this information on a staging form or in the medical record.

#### Codes

0 =	Stage 0	2B =	Stage IIB
0A =	Stage 0A	2C =	Stage IIC
0S =	Stage 0is	3 =	Stage III
1 =	Stage I	3A =	Stage IIIA
1A =	Stage IA	3B =	Stage IIIB
A1 =	Stage T1A1	3C =	Stage IIIC
A2 =	Stage T1A2	4 =	Stage IV
1B =	Stage T1B	4A =	Stage IVA
B1 =	Stage T1B1	4B =	Stage IVB
B2 =	Stage T1B2	4C =	Stage IVC*
1C =	Stage IC	88 =	Not applicable
1S =	Stage IS	OC =	Occult
2 =	Stage II	99 =	Recurrent, unstaged, unknown, Stage X
2A =	Stage IIA		-

#### Instructions

a. Refer to the specific site in the AJCC manual for the conversion of TNM groupings into stage. Enter the code for the stage category that represents the clinical TNM combination previously coded.

Example: A breast cancer with T2, N1, M0 would be coded as a Stage IIB and entered as 2B.

- b. If the stage code is only one digit, record to the left and leave the second space blank (left justify). Truncate the least significant subdivision of the category from the right as needed.
- c. Choose the lower (less advanced) stage grouping when there is any uncertainty. Refer to the *AJCC Cancer Staging Manual* for coding rules.
- d. Convert all Roman numerals to Arabic numerals.

```
Example 1: Stage IV converts to stage 4. Example 2: Stage IIA converts to stage 2A.
```

e. Record 88 when the site or histologic type does not have an AJCC staging scheme.

Examples: Leukemia, dermatofibrosarcoma, unknown primary site, etc. The pathology report identifies a breast mass as sarcoma. The breast staging scheme in the AJCC Cancer Staging Manual applies only to carcinomas. Record Stage Group 88.

- f. Record 88 for clinical T, N, M, and stage group if pediatric staging is used and AJCC staging is not applied. If AJCC staging was applied for a pediatric tumor, record the appropriate codes and do not code 88.
- g. Record 99 when the site or histologic type has an AJCC staging scheme but there is not enough information to assign a stage group.
  - Example: A patient has a fine-needle biopsy of a breast mass. The cytology identifies infiltrating ductal carcinoma. The medical record does not describe tumor size. The AJCC staging elements are TX NX MX. The stage group cannot be assigned. Record 99.
- h. The grade/differentiation or the size of tumor is necessary to determine the stage grouping in several sites. Refer to the current *AJCC Cancer Staging Manual*.

#### Clinical Stage (Prefix/Suffix) Descriptor

Clinical Stage Descriptor is an optional field in the RMCDS screen for a FORDS data item. The FORDS descriptors identify special cases that need separate data analysis. The descriptors are adjuncts to and do not change the stage group. The State Registry does not collect the item. For coding instructions on Clinical Stage Descriptors, refer to the FORDS, page 116.

## 48. STAGED BY (CLINICAL STAGE) Item Length: 1 ACoS: Required State Registry: Optional

#### **Description**

This is an optional 1-character field for recording a code that identifies the person who assigned the clinical AJCC staging elements and the stage group. Facilities that do not collect this item may leave the field blank. The State Registry does not collect the item.

#### Rationale

Data captured in this field can be used to evaluate the accuracy and completeness of physician staging and form the basis for quality management and improvement studies.

#### Codes

- 0 Not staged
- 1 Managing physician
- 2 Pathologist
- 3 Pathologist and managing physician
- 4 Cancer Committee chair, cancer liaison physician, or registry physician advisor
- 5 Cancer registrar
- 6 Cancer registrar and physician
- 7 Staging assigned at another facility
- 8 Case is not eligible for staging
- 9 Unknown; not stated in the patient record

#### **Definitions**

CODES	DEFINITIONS
0	Staging was not assigned.
1	Staging was assigned by the managing physician.
2	Staging was assigned by the pathologist only.
3	Staging was assigned by the pathologist and the managing physician.
4	Staging was assigned by the Cancer Committee chair, cancer liaison physician, or the registry physician advisor during a quality control review.
5	Staging was assigned by the cancer registrar only.
6	Staging was assigned by the cancer registrar and any of the physicians specified in codes 1-4.
7	Staging was assigned by a physician at another facility.
8	An AJCC staging scheme has not been developed for this site. The histology is excluded from an AJCC site scheme.
9	It is unknown whether or not the case was staged.

49.	PATHOLOGIC T	Item Length: 2 Data Type: Alphanumeric Left Justified, Blank Fill ACoS: Required State Registry: Optional
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#### Description

This is an optional 2-character field for recording a code for the pathologic T classification. The pathologic T evaluates only the primary tumor and reflects tumor size and/or extension.

#### **Definitions**

- a. Pathologic classification is based on information obtained before treatment and supplemented by additional evidence from surgery and pathologic examination of the resected specimen. It is a combination of all findings. The pathologic stage provides the most precise data to estimate prognosis and calculate end results. Pathologic assessment of the primary tumor requires a resection of the primary tumor or a biopsy adequate to evaluate the highest pT (pathologic Tumor) category. The pathologic assessment of the regional lymph nodes requires the removal of enough nodes to confirm the absence of regional lymph node metastasis and evaluate the highest pN (pathologic Nodes) category.
- b. Pathologic staging takes precedence over clinical staging.
  - **Exception:** There are some diseases and sites for which clinical staging takes precedence. Clinical staging takes precedence when the patient has radiation or chemotherapy preoperatively and when the patient does not have cancer-directed surgery.

Example 1: Cervical cancer treated pre-operatively with radiation.

Example 2: Breast cancer treated pre-operatively with chemotherapy and radiation.

Example 3: Prostate cancer biopsied and treated with hormones.

Example 4: Small cell carcinoma of the lung biopsied and treated with chemotherapy.

Example 5: Pancreas primary diagnosed without histologic confirmation.

- c. The following general definitions are used throughout the TNM classification:
  - TX Primary tumor cannot be assessed or is unknown
  - To No evidence of a primary tumor
  - Tis Carcinoma in situ
  - T1, T2, T3, and T4 describe increasing size and/or local extent of the primary tumor

#### Codes

X =	TX	2 =	T2
0 =	T0	2A =	T2a
A =	Ta	2B =	T2b
IS =	Tis	2C =	T2c
SU =	Tis pu	3 =	T3
SD =	Tis pd	3A =	T3a
1M =	T1mic	3B =	T3b
1 =	1	3C =	T3c
1A =	T1a	4 =	T4
A1 =	T1a1	4A =	T4a
A2 =	T1a2	4B =	T4b
1B =	T1b	4C =	T4c
B1 =	T1b1	4D =	T4d
B2 =	T1b2	88 =	Not applicable (no AJCC staging scheme)
1C =	T1c		

#### Instructions

- a. Enter the T (Tumor) code for the primary tumor. This item is a one or two digit code. If the code is only one digit, enter it in the first space (left justify) and leave the second space blank. Truncate the least significant subdivision of the category from the right as needed (see example under Nodes section).
- b. Choose the lower (less advanced) T category when there is any uncertainty. Refer to the *AJCC Cancer Staging Manual* for coding rules.
- c. Tumor size is necessary to classify T for several sites.
- d. Record 88 when the site or histologic type does not have an AJCC staging scheme.
  - Examples: Leukemia, lymphoma, dermatofibrosarcoma, etc. The pathology report identifies a breast mass as sarcoma. The breast staging scheme in the AJCC Cancer Staging Manual applies only to carcinomas. Record T88.
- e. Record X when the site or histologic type has an AJCC staging scheme but there is not enough information to assign a T value.
  - Example: A patient has a fine-needle biopsy of a breast mass. The cytology identifies infiltrating ductal carcinoma. The patient is lost to follow-up. AJCC staging requires a pathologic tumor size and examination of at least one axillary node for pathologic staging. Record TX NX MX.

50.	PATHOLOGIC N	Item Length: 2 Data Type: Alphanumeric Left Justified, Blank Fill ACoS: Required State Registry: Optional
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#### **Description**

This is an optional 2-character field to record a code for the pathologic N classification. The pathologic N identifies the absence or presence of regional lymph node metastases and describes the extent of regional lymph node metastases.

#### **Definitions**

The following general definitions are used throughout the TNM classification:

NX Regional lymph nodes cannot be assessed or status is unknown.

NO Nodes were assessed and there was no evidence of regional lymph node metastasis.

N1, N2, and N3 indicate increasing involvement of regional lymph nodes.

#### Codes

X =	NX	2 =	N2
0 =	N0	2A =	N2a
0 =	N0(i-)	2B =	N2b
0 =	N0(i+)	2C =	N2c
0 =	N0(mol-)	3 =	N3
0 =	N0(mol+)	3A =	N3a
1 =	N1	3B =	N3b
1A =	N1a	3c =	N3c
1B =	N1b	88 =	Not applicable (no AJCC staging scheme)
1C =	N1c		
1M =	N1mi		

#### Instructions

a. Enter the N (Nodes) code with the appropriate suffix for regional lymph node involvement that describes the absence of involvement or increasing degrees of involvement. This item is a one or two digit code. If the code is only one digit, enter it in the first space (left justify) and leave the second space blank. Truncate the least significant subdivision of the category from the right as needed.

Example: N1biii is entered as 1B. The N is omitted and the iii is truncated (cut off) from the right, since only 2 digits can be entered.

- b. Choose the lower (less advanced) N category when there is any uncertainty. Refer to the *AJCC Cancer Staging Manual* for coding rules.
- c. Classify a primary tumor that directly extends into lymph nodes as lymph node metastasis.
- d. Record 88 when the site or histologic type does not have an AJCC staging scheme.

Examples: Leukemia, lymphoma, dermatofibrosarcoma, etc. The pathology report identifies a breast mass as sarcoma. The breast staging scheme in the AJCC Cancer Staging Manual applies only to carcinomas. Record N88.

e. Record X when the site or histologic type has an AJCC staging scheme but there is not enough information to assign an N value.

Example: A patient has a biopsy of a testicular mass. The biopsy identifies embryonal carcinoma. The patient is lost to follow-up. AJCC staging requires a radical orchiectomy with lymph node dissection for pathologic staging. Record pTX NX MX.

#### 51. PATHOLOGIC M

Item Length: 2

Data Type: Alphanumeric Left Justified, Blank Fill ACoS: Required State Registry: Optional

#### Description

This is an optional 2-character field to record a code for the pathologic M classification. The pathologic M records the presence or absence of distant metastases.

#### **Definitions**

The following general definitions are used throughout the TNM classification:

MX The presence of distant metastasis cannot be assessed or is unknown

M0 No known distant metastasis

M1 Distant metastases are present

#### Codes

X = MX

0 = M0

1 = M1

1A = M1a

1B = M1b

1C = M1c

88 = Not applicable (no AJCC staging scheme)

#### Instructions

- a. Enter the M (Metastasis) code for the presence or absence of distant metastasis. This item is a one or two digit code. If the code is only one digit, enter it in the first space (left justify) and leave the second space blank. Truncate the least significant subdivision of the category from the right as needed.
- b. Choose the lower (less advanced) M category when there is any uncertainty. Refer to the *AJCC Cancer Staging Manual* for coding rules.
- c. Record 88 when the site or histologic type does not have an AJCC staging scheme.
  - Examples: Leukemia, lymphoma, dermatofibrosarcoma, etc. The pathology report identifies a breast mass as sarcoma. The breast staging scheme in the AJCC Cancer Staging Manual applies only to carcinomas. Record M88.
- d. Record X when the site or histologic type has an AJCC staging scheme but there is not enough information to assign an M value.
  - Example: A patient has a fine-needle biopsy of a breast mass. The cytology identifies infiltrating ductal carcinoma. The patient is lost to follow-up. AJCC staging requires tumor size and palpation of axillary lymph nodes for clinical staging. Record TX NX MX.
- e. When a patient with multiple primaries develops metastases, a biopsy may distinguish the source of distant disease. Stage both primaries as having metastatic disease if the physician is unable to conclude which primary has metastasized. If the physician later identifies which primary has metastasized, update the stage(s) as appropriate.

# 52. PATHOLOGIC STAGE GROUP Item Length: 2 Data Type: Alphanumeric Left Justified, Blank Fill ACoS: Required State Registry: Optional

#### Description

This is an optional 2-character field for recording a code that condenses the pathologic T, N, and M elements into categories for purposes of tabulation and analysis. It defines the anatomic extent of disease based on the previously coded T, N, and M elements. The information should be reported if you are already collecting it, e.g., if your hospital has a cancer program approved by the American College of Surgeons, Commission on Cancer.

The TNM (Tumor, Nodes, Metastasis) Stage Grouping codes are from the *AJCC Cancer Staging Manual*. Efforts should be made to capture this information on a staging form or in the medical record.

#### Codes

0 =	Stage 0	2A =	Stage IIA
0A =	Stage 0A	2B =	Stage IIB
0S =	Stage 0is	2C =	Stage IIC
1 =	Stage I	3 =	Stage III
1A =	Stage IA	3A =	Stage IIIA
A1 =	Stage T1A1	3B =	Stage IIIB
A2 =	Stage T1A2	3C =	Stage IIIC
1B =	Stage T1B	4 =	Stage IV
B1 =	Stage T1B1	4A =	Stage IVA
B2 =	Stage T1B2	4B =	Stage IVB
1C =	Stage IC	4C =	Stage IVC*
1S =	Stage IS	88 =	Not applicable
2 =	Stage II	99 =	Recurrent, unstaged, unknown, Stage X

#### Instructions

a. Refer to the specific site in the AJCC manual for the conversion of TNM groupings into stage. Enter the code for the stage category that represents the pathologic TNM combination previously coded.

Example: A breast cancer with T2, N1, M0 would be coded as a Stage IIB and entered as 2B.

- b. If pathologic M is coded as either X or blank and clinical M is coded as 0, 1, 1A, 1B, or 1C, then the combination of staging elements pT, pN, and cM may be used to complete the pathologic stage group.
- c. If the stage code is only one digit, record to the left and leave the second space blank (left justify). Truncate the least significant subdivision of the category from the right as needed.
- d. Choose the lower (less advanced) stage grouping when there is any uncertainty. Refer to the *AJCC Cancer Staging Manual* for coding rules.
- e. Convert all Roman numerals to Arabic numerals.

```
Example 1: Stage IV converts to stage 4. Example 2: Stage IIA converts to stage 2A.
```

f. Record 88 when the site or histologic type does not have an AJCC staging scheme.

- Examples: Leukemia, dermatofibrosarcoma, unknown primary site, etc. The pathology report identifies a breast mass as sarcoma. The breast staging scheme in the AJCC Cancer Staging Manual applies only to carcinomas. Record Stage Group 88.
- g. Record 88 for pathologic T, N, M, and stage group if pediatric staging is used and AJCC staging is not applied. If AJCC staging was applied for a pediatric tumor, record the appropriate codes and do not code 88.
- h. Record 99 when the site or histologic type has an AJCC staging scheme but there is not enough information to assign a stage group.
  - Example: A patient has a fine-needle biopsy of a breast mass. The cytology identifies infiltrating ductal carcinoma. The medical record does not describe tumor size. The AJCC staging elements are TX NX MX. The stage group cannot be assigned. Record 99.
- i. The grade/differentiation or the size of tumor is necessary to determine the stage grouping in several sites.

#### Pathologic Stage (Prefix/Suffix) Descriptor

Pathologic Stage Descriptor is an optional field in the RMCDS screen for a FORDS data item. The FORDS descriptors identify special cases that need separate data analysis. The descriptors are adjuncts to and do not change the stage group. The State Registry does not collect the item. For coding instructions on Pathologic Stage Descriptors, refer to the FORDS, page 122.

### 53. STAGED BY (PATHOLOGIC STAGE)

ACoS: Required State Registry: Optional

Item Length: 1

#### Description

This is an optional 1-character field for recording a code that identifies the person who assigned the pathologic AJCC staging elements and the stage group. Facilities that do not collect this item may leave the field blank. The State Registry does not collect the item.

#### Rationale

Data captured in this field can be used to evaluate the accuracy and completeness of physician staging and form the basis for quality management and improvement studies.

#### Codes

- 0 Not staged
- 1 Managing physician
- 2 Pathologist
- 3 Pathologist and managing physician
- 4 Cancer Committee chair, cancer liaison physician, or registry physician advisor
- 5 Cancer registrar
- 6 Cancer registrar and physician
- 7 Staging assigned at another facility
- 8 Case is not eligible for staging
- 9 Unknown; not stated in the patient record

#### **Definitions**

CODES	DEFINITIONS
0	Staging was not assigned.
1	Staging was assigned by the managing physician.
2	Staging was assigned by the pathologist only.
3	Staging was assigned by the pathologist and the managing physician.
4	Staging was assigned by the Cancer Committee chair, cancer liaison physician, or the registry physician advisor during a quality control review.
5	Staging was assigned by the cancer registrar only.
6	Staging was assigned by the cancer registrar and any of the physicians specified in codes 1-4.
7	Staging was assigned by a physician at another facility.
8	An AJCC staging scheme has not been developed for this site. The histology is excluded from an AJCC site scheme.
9	It is unknown whether or not the case was staged.

#### Instruction

If stage group is coded 99, record the applicable code for whoever assigned the 99 value.

TEXT FIELDS FOR WORKUP	
DX PROCEDURES X-RAY/SCANS	Data Type: Text
DX PROCEDURES LAB TEXTS	Data Type: Text
HISTORY AND PHYSICAL	Data Type: Text
SURGICAL STAGING PROCEDURES	Data Type: Text
DIAGNOSTIC SCOPE PROCEDURES	Data Type: Text
	ACoS: N/A State Registry: Optional

#### Description

The fields listed above are optional text fields in the RMCDS abstract screen for recording information from the work-up for the tumor being reported. Facilities using the paper abstract may record this information in the field, *Remarks*. Facilities using other types of registry software should follow their vendor's instructions for recording text about the work-up. Although the items are optional, abstractors are strongly encouraged to document work-up that provides information about the malignancy or extent of disease that has not been recorded in other text fields.

#### Instructions

#### Dx Procedures X-rays/Scans

- a. Record documentation from all X-ray, scans, and/or other imaging examinations that provide information about the malignancy or extent of disease.
- b. Include, as applicable: Dates, primary site, histology, tumor location, tumor size, lymph nodes, positive and negative findings, and distant disease or metastasis.

#### Dx Procedures Lab Tests

- a. Record documentation from laboratory examinations other than cytology or histopathology. Tests can include tumor markers, serum and urine electrophoresis, special studies, etc.
- b. Include, as applicable: Type of laboratory test/specimen(s), date(s) of test(s), and positive and negative findings.

#### History and Physical

- a. Record documentation from the history and physical examination about the history and clinical description of the current tumor.
- b. Include, as applicable: Date of physical exam; age, sex, race/ethnicity; history that relates to cancer diagnosis; primary site; histology (if diagnosed prior to this admission); tumor location; tumor size; palpable lymph nodes; positive and negative clinical findings; impression pertaining to cancer diagnosis; and treatment plan.

#### Surgical Staging Procedures

- a. Record documentation of all surgical diagnostic and staging procedures.
- b. Include, as applicable: Dates and descriptions of biopsies and all other surgical procedures from which staging information was derived; number of lymph nodes removed; size of tumor removed; documentation of residual tumor; evidence of invasion of surrounding areas.

#### Diagnostic Scope Procedures

- Record documentation from endoscopic examinations that provide information for staging and treatment.
- b. Include, as applicable: Date(s) of endoscopic exam(s); primary site; histology; tumor location; tumor size; lymph nodes; and positive and negative clinical findings.

#### GENERAL DEFINITIONS AND RULES FOR CODING TREATMENT

a. Definitive (cancer-directed) treatment is any therapy whose purpose is to modify, control, remove, or destroy proliferating cancer tissue. Treatment may be directed toward either the primary or metastatic sites, regardless of the patient's response.

Record all cancer-directed treatment administered to the patient in the first course of treatment. Include treatment provided in other facilities and failed treatments (the patient did not respond).

For statistical analysis of treatment, only the following codes are considered definitive treatment codes:

- 10-90 Surgery (removal of tumor cells)
- 20-98 Regional radiation treatment modality (destruction of cancer cells through rays, radons)
- 01-03 Chemotherapy (destruction of cancer cells through chemicals, drugs)
- O1 Hormone/steroid (endocrine) therapy (changing hormonal balance through hormones, steroids, or endocrine surgery)
- O1 Immunotherapy or Biological Response Modifier therapy (agents that alter the immune system or change the host response)
- 10-40 Hematologic transplant and endocrine procedures
- 1-3 Other cancer-directed therapy (nonspecific or experimental)

Codes that indicate a specific definitive treatment is not recommended, recommended but not given, or unknown whether recommended or given may be recorded in the treatment fields listed below.

- (1) Chemotherapy codes 82-99
- (2) Hormone Therapy codes 82-99
- (3) Immunotherapy (Biological Response Modifier) codes 82-99
- (4) Other Therapy codes 7, 8, and 9
- (5) Hematologic Transplant and Endocrine Procedure codes 82-99
- b. **Non-definitive (non cancer-directed) treatments** are performed to establish a diagnosis or stage, relieve symptoms, prolong the patient's life, or prepare the patient for cancer-directed therapy. Such treatments are not considered cancer-directed treatment. There is no expectation of reducing the size of the tumor or of delaying the spread of the disease. In effect, it is treatment of the patient, not the cancer.

The following examples of non-definitive treatment are  $\underline{not}$  considered cancer-directed therapy, but can be recorded in the designated fields, when applicable.

- (1) Surgical Diagnostic and Staging Procedure codes 01 09. Refer to page 180. These procedures include:
  - Incisional biopsies
  - Exploratory procedures with or without biopsies
  - -otomy, -ostomy, or bypass only
- (2) Palliative Care codes 1-9 (Not collected by the State Cancer Registry refer to the FORDS.)

The following treatments are also considered non-definitive therapies and are not coded:

- (1) Pain medication
- (2) Oxygen
- (3) Antibiotics administered for an associated infection
- (4) Transfusions (e.g., to counteract blood dyscrasia resulting from chemotherapy)
- (5) Medication (e.g., Epogen, Neupogen, or Procrit) to counteract blood dyscrasia resulting from chemotherapy
- (6) Intravenous therapy to maintain fluid or nutritional balance
- (7) Laser therapy directed at relieving symptoms
- (8) Closure of colostomy in a patient with prior resection for cancer of the bowel
- (9) Megestrol acetate, hormone therapy designed to improve nutritional status

#### c. First Course of Treatment

All cancer-directed therapies specified in the physician(s) treatment plan during or after the initial diagnosis are part of the first course of treatment. Documentation of a treatment plan may be found in several different sources, for example: medical clinic record, consultation reports, and outpatient records. The discharge plan may document all or part of the treatment plan.

(1) For <u>all malignancies except leukemias</u>, first course of treatment includes all methods of therapy recorded in the treatment plan and administered to the patient during or after the first diagnosis of cancer. Planned treatment may include multiple modes of therapy and may encompass intervals of a year or more.

If the therapy is a part of an established protocol or administered within accepted management guidelines for the disease, it is first course of treatment. When a treatment plan is not available or is unclear, consult the physician advisor.

If there is no treatment plan, established protocol, or management guidelines, and consultation with a physician advisor is not possible, use the principle: "Initial treatment must begin within four months of the date of initial diagnosis."

(2) For <u>leukemias</u>, first course of treatment includes all methods of therapy recorded in the treatment plan and administered to the patient during or after the first diagnosis of leukemia. Record all remission-inducing or remission-maintaining cancer-directed therapy as first course of treatment. Treatment regimens may include multiple modes of therapy and may encompass intervals of a year or more. Certain pediatric leukemia protocols span two years or more from induction to the end of maintenance. In these protocols, induction, consolidation, and maintenance are all first course of treatment.

If the therapy for leukemia is a part of an established protocol or administered within accepted management guidelines for the disease, it is first course of treatment. When a treatment plan is not available or is unclear, consult the physician advisor.

A patient may relapse after achieving a first remission. All therapy administered after the relapse is secondary or subsequent treatment.

#### d. No Treatment

No therapy is a treatment option (the patient refused therapy, the family/guardian refused therapy, the patient expired before therapy started, or the physician recommended no therapy). Therefore, first course of treatment may be no treatment. Record the date the decision was made not to treat in *Date of First Course of Treatment*.

e. **Treatment for Recurrence or Progression** (subsequent treatment) includes all treatments administered after the first course of therapy is complete or was stopped. A physician may stop treatment if the disease progresses despite therapy or if the patient fails to respond. The patient may also choose to stop treatment. If therapy is not part of the <u>planned</u> first course of treatment, it is considered subsequent therapy.

If there is a change in the original planned or administered treatment because the patient does not respond or the disease progresses, such therapy should be excluded from the first course of therapy and be considered as part of a second or subsequent course of therapy.

The State Cancer Registry does not require facilities to report subsequent therapy. The RMCDS program includes "Subsequent Treatment" screens for facilities that choose to report it.

#### f. Treatment Dates

- (1) If your software allows collection of information for only one cancer-directed surgery, record the first date on which the patient has cancer-directed surgery. Record the surgery code with the highest priority according to the rules listed on page 190 of this manual.
- (2) If the exact date that therapy was started is not known, the <u>best estimate</u> based on available information is acceptable. In the absence of an exact date of treatment, the date of hospital admission for the first cancer-directed therapy is acceptable. Recording an approximate date is preferable to recording an unknown date.
- (3) If there is no basis for estimating, code both month and day 99. Every attempt should be made to enter the month and year, even if an estimate is necessary. In those rare instances when it is necessary to enter unknown month, day, or year, enter 9's in the appropriate spaces.

If information is limited to a description, use the following:

DESCRIPTIVE TERM USED	DATE CODE
Spring	April
The middle of the year	July
Fall	October
Winter	Try to determine if this means the beginning of the year (January) or the end of the year (December). Code as indicated.

- (4) If cancer-directed therapy was initiated at another facility (e.g., class of case is 0 or 3) and you cannot approximate the date it began, enter all 9's. If you do know the exact date, you should record it, even if the therapy did not take place at your facility.
- (5) If the <u>documented</u>, <u>planned first course of therapy</u> occurred after four months, enter the date this planned first course of therapy was initiated, even if it was initiated after four months from the date of initial diagnosis.
- (6) If class of case is 5 (diagnosed at autopsy), do not record any treatment or treatment dates. *Date of First Course Treatment* would be coded 00/00/0000.

#### 54. SURGICAL DIAGNOSTIC AND STAGING PROCEDURES

Item Length: 2 Data Type: Numeric ACoS: Required

State Registry: Required

#### **Description**

Surgical procedure(s) performed in the work-up to diagnose and/or stage disease. The item is used to track the use of surgical procedure resources that are not considered treatment.

- 00 No surgical diagnostic or staging procedure was performed.
- 01 A biopsy (incisional, needle, or aspiration) was done to a site other than the primary. No exploratory procedure was done.
- 02 A biopsy (incisional, needle, or aspiration) was done to the primary site.
- 03 A surgical exploration only. The patient was not biopsied or treated.
- 04 A surgical procedure with a bypass was performed, but no biopsy was done.
- 05 An exploratory procedure was performed, and a biopsy of either the primary site or another site was done.
- 06 A bypass procedure was performed, and a biopsy of either the primary site or another site was done.
- 07 A procedure was done, but the type of procedure is unknown.
- 09 No information of whether a diagnostic or staging procedure was performed.

#### Instructions

- a. Record the type of procedure performed as part of the initial diagnosis and work-up, whether this is done at your facility or another facility.
- b. If both an incisional biopsy of the primary site and an incisional biopsy of a metastatic site are done, use code 02 (Incisional biopsy of primary site).
- c. Do not code surgical procedures that aspirate, biopsy, or remove regional lymph nodes in an effort to diagnose and/or stage disease in this data item. Use the data item Scope of Regional Lymph Node Surgery to code these procedures. Do not record the date of surgical procedures that aspirate. biopsy, or remove regional lymph nodes in the data item Date of Surgical Diagnostic and Staging Procedure. See instructions for Scope of Regional Lymph Node Surgery.
- d. Do not code brushing, washings, cell aspiration, or hematologic findings (peripheral blood smears). These are not considered surgical procedures and should not be coded in this item.
- e. Do not code excisional biopsies with clear or microscopic margins in this data item. Use the data item Surgical Procedure of Primary Site to code these procedures.
- Do not code palliative surgical procedures in this data item. Use the *Palliative Care* field to code these procedures. The State Registry does not collect Palliative Care. Refer to the FORDS manual for codes.

#### Codes with Examples:

- 00 A lung cancer primary was diagnosed by CT scan. The patient expired. No surgical diagnostic or staging surgical procedure was performed.
- 00 A sputum sample is examined cytologically to confirm a diagnosis of suspected lung cancer. The procedure is not surgical
- 01 A thoracentesis is performed on a patient to stage a lung primary. The withdrawn fluid is examined cytologically for confirmation of malignant pleural effusion.
- O1 A needle biopsy of a liver metastasis in a patient with suspected widespread colon cancer was done. Gross residual tumor is left at the biopsy site.
- 02 During a colonoscopy, a biopsy of a primary rectal mass was done. Gross residual tumor is left at the biopsy site.
- 03 During abdominal exploratory surgery, a gastric lesion and suspicious retroperitoneal lymph nodes were observed. No biopsy or treatment was done.
- 04 An abdominal exploration of a patient revealed pancreatic carcinoma with extension into surrounding organs and arteries. There was no attempt to treat. A bypass was performed to alleviate symptoms.
- 05 An exploratory procedure was performed for primary colon carcinoma with biopsy of suspicious liver lesions.
- 06 Esophagogastrostomy was performed for infiltrating gastric tumor following a biopsy of the primary site.
- 07 Stage III lung carcinoma was diagnosed and staged prior to admission.
- 09 A patient expires in the emergency room with recently diagnosed metastatic melanoma. It is unknown whether a diagnostic or staging procedure was done.

#### 55. DATE OF FIRST COURSE OF TREATMENT

Item Length: 8 Data Type: Numeric ACoS: Required

State Registry: Required

#### Description

This is a required 8-character field for recording the date on which treatment (surgery, radiation, systemic, or other therapy) of the patient began at any facility.

#### Codes

	<u>Month</u>	<u>Day</u>	<u>Year</u>
00		00	0000
01	January	01	Use four-digit year (e.g., 2003)
02	February	02	9999 Year unknown
03	March	03	
04	April		
05	May		
06	June	25	
07	July	26	
80	August		
09	September	30	
10	October	31	
11	November	99 Day unknowr	n
12	December	-	
99	Month unknown		

#### **Special Codes**

00000000 Diagnosed at autopsy.

99999999 Unknown whether any treatment was administered to the patient; the date is unknown; or the case was identified by death certificate only.

#### Instructions

- a. Record the earliest of the following dates: Date of First Surgical Procedure, Date Radiation Started, Date Chemotherapy Started, Date Hormone Therapy Started, Date Immunotherapy Started, Date of Hematologic Transplant and Endocrine Procedure, or Date Other Treatment Started. Record the earliest treatment date, whether it occurs at your facility or elsewhere. For example, if the patient receives preoperative radiation elsewhere before admission to your facility for surgery, record the date of the preoperative radiation.
- b. Record the month, day, and year (MM/DD/YYYY) the first course therapy was started. Fill in with leading zeros where needed. For example, record June 3, 2003 as 06/03/2003.
- c. If the exact date of the beginning of treatment is not available, record an approximate date. If information is limited to a description, use the following:

DESCRIPTIVE TERM USED	DATE CODE
Spring	April
The middle of the year	July
Fall	October
Winter	Try to determine if this means the beginning of the year (January) or the end of the year (December). Code as indicated.

d. In cases of non-treatment, in which a physician decides not to treat a patient or a patient's family or quardian declines all treatment, record the date this decision was made.

- e. Do <u>not</u> record the date of incisional, core, or fine needle biopsy in this field, even if it is the only procedure performed.
- f. Record the date of an <a href="excisional">excisional</a> biopsy as the Date of First Course of Treatment, whether followed by further definitive therapy or not. The excisional biopsy date will remain Date of First Course of Treatment even when followed by other surgery of the primary site. Enter the date of the excisional biopsy, whether or not residual tumor was found at the time of later resection. If the biopsy was not stated to be excisional, but no residual tumor was found at a later resection, assume that the biopsy was excisional. Use the date of admission if an exact treatment date is not obtainable for the excisional biopsy.

Example: A breast cancer patient has an excisional biopsy on June 26, 2003. The patient has a modified radical mastectomy July 5, 2003. Record June 26, 2003 in the *Date of First Course of Treatment* field.

#### GENERAL INSTRUCTIONS FOR RMCDS TREATMENT FIELDS

#### Description

Ten hospital-specific first course treatment screens are available in the RMCDS *FORDS* version for recording first course treatment provided at the reporting facility and/or other facilities. Each of the screens is similar to the illustration provided below and includes fields for recording the facility where the treatment occurred, the codes for the various treatment modalities, and the respective dates of treatment. The first available screen is opened by double clicking on the *First Course Treatment* field or by using the "Alt" and "T" keys. The "Next" button will open an additional first course treatment screen only if data has been entered in the current screen. Use the "Exit" button or the "Esc" key to close the treatment screens.

First Course Treatment		X
Hospital	☐ Delete	Print
Dx/Stage Proc Date / /  Surgery Date / /  Radiation Date / /  Chemotherapy Date / /  Hormonal Date / /		Old Old Old Old Old Old Old
BRM Date / / Other Date / /		Old Old
Scope of Lymph Node Surgery  Surgery of Other Sites		Old Old
Location of Radiation		Reg LN Examined Screen/Bx
Previous Next		Exit

**Note:** State required treatment items that are not hospital specific (*Date of First Course Treatment*, Regional Radiation Treatment Modality, Hematologic Transplant and Endocrine Procedures, and the treatment text fields) appear in the other RMCDS screens. Use the FORDS treatment codes defined in this manual for Regional Radiation Treatment Modality and Hematologic Transplant and Endocrine Procedures, regardless of diagnosis date.

#### Instructions for Cases Diagnosed 01/01/2003 or Later

a. Hospital (Refer to Appendix D of this manual for facility identification (ID) numbers.) If any of the treatment modalities were provided at your facility, record your facility number in the hospital field. If more than one surgery of the primary site are performed at your facility, use the other "First Course Treatment" screen(s) as needed.

If additional treatment is known to have been provided at other facility(ies), use the other "First Course Treatment" screen(s) as needed, recording the facility's ID number or 999. Code facility ID as 700 for treatment provided in a physician's office. If the only known treatment was provided at another facility, use the first available screen. If it is unknown where the treatment occurred, record code 999.

Surgical Diagnostic and Staging Procedure
 Record the appropriate Surgical Diagnostic and Staging Procedure code from the list on page 180 of
 this manual.

#### c. Treatment Modality Fields

Record the appropriate treatment code(s) from the applicable list(s) in this manual for *Surgery of Primary Site*, *Chemotherapy*, *Hormone Therapy*, *Biological Response Modifier*, *or Other Treatment*. *Radiation* is an optional field for the item of the same name from the *ROADS* or the 1998 State manual. Facilities that chose to collect this item should use the codes listed on page 199 of this manual.

#### d. Dates

Record the eight-character date (MM/DD/YYYY) that the treatment was performed or started in the date field adjacent to the applicable treatment code. Fill with leading zeros where needed (e.g., record June 3, 2003 as 06/03/2003). If the patient received no treatment, leave the date field blank.

#### e. Old

Leave the fields blank for cases diagnosed 01/01/2003 or later.

#### f. Scope of Lymph Node Surgery

Record the appropriate Scope of Lymph Node Surgery code from the list on page 192 of this manual.

#### g Surgery of Other Sites

Record the appropriate Surgery of Other Sites code from the list on page 194 of this manual.

#### h. Palliative Procedure (Palliative Care)

Palliative Procedure (Palliative Care) is an optional item. Facilities that wish to collect it should use the codes defined in the FORDS manual.

#### i. Location of Radiation

Location of Radiation is an optional item. Facilities that wish to collect it should use the codes defined in the FORDS manual.

#### i. Surgical Approach

Leave the field blank for cases diagnosed 01/01/2003 or later.

#### k. Regional Lymph Nodes Examined

Leave the field blank for cases diagnosed 01/01/2003 or later.

#### I. Screening/Biopsy Procedure

Leave the field blank for cases diagnosed 01/01/2003 or later.

#### Instructions for Abstracting Cases Diagnosed Before 01/01/2003

- a. For cases diagnosed before 01/01/2003 and entered prior to conversion to the *FORDS* version, treatment fields will be completed and converted automatically.
- b. For cases diagnosed before 01/01/2003 and entered after the conversion, treatment may be entered into the *FORDS* screens in one of two ways as described below. **Note:** Only option one is possible at the time of this printing.

#### (1) Option one:

Record both *FORDS* and *ROADS* codes (*ROADS* in the *Old* fields), as applicable, for the following items:

Surgery of Primary Site

Scope of Regional Lymph Node Surgery

Surgery of Other Site

Record only *ROADS* codes, as applicable, for the following items:

Radiation

Number of Regional Lymph Nodes Examined (optional)

Surgical Approach (optional)

Record FORDS codes, as applicable, for all other treatment items.

(2) Option two (Not available at the time of this printing):
Complete the applicable *Old* fields using *ROADS* codes and record treatment dates in the date fields on the left. The system will complete the *FORDS* treatment fields by converting the recorded *ROADS* codes when the case is exited.

#### **Subsequent Treatment**

Ten subsequent treatment screens are available in the RMCDS program. The first available screen is opened by using the Alt and "Q" keys. Subsequent treatment is optional for reporting to the State Registry. Because subsequent treatment is not included in the *FORDS* data set, facilities that want to record it must use *ROADS* codes.

### 56. SURGICAL PROCEDURE OF PRIMARY SITE (CANCER-DIRECTED SURGERY)

Item Length: 2
Data Type: Numeric
ACoS: Required
State Registry: Required

#### **Description**

This is a required 2-character field to record the surgery performed as a part of the first course of therapy. You <u>must</u> record all procedures done at your facility, and you <u>should</u> record procedures done at other facilities, if known.

#### Codes

There are site-specific surgery codes in Appendix I for the sites listed in the following table. Definitions and rules for the surgery codes are provided at the beginning of Appendix I.

ICD-O-3 CODE	SITE
C00.0 - C06.9	Oral cavity
C07.9 - C08.9	Parotid and other unspecified glands
C09.0 - C14.0	Pharynx
C15.0 - C15.9	Esophagus
C16.0 - C16.9	Stomach
C18.0 - C18.9	Colon
C19.9	Rectosigmoid
C20.9	Rectum
C21.0 - C21.8	Anus
C22.0 - C22.1	Liver and intrahepatic bile ducts
C25.0 - C25.9	Pancreas
C32.0 - C32.9	Larynx
C34.0 - C34.9	Bronchus and lung
C42.0, C42.1, C42.3, C42.4	Hematopoietic/Reticuloendothelial/Immunoproliferative/Myeloproliferative Disease
C40.0 - C41.9	Bones, joints, and articular cartilage
C42.2	Spleen
C44.0 - C44.9	Skin
C47.0 - C47.9	Peripheral nerves and autonomic nervous system
C49.0 - C49.9	Connective, subcutaneous, and other soft tissues
C50.0 - C50.9	Breast
C53.0 - C53.9	Cervix uteri
C54.0 - C54.9	Corpus uteri
C56.9	Ovary
C61.9	Prostate
C62.0 - C62.9	Testis
C64.9	Kidney
C65.9	Renal pelvis
C66.9	Ureter
C67.0 - C67.9	Bladder

ICD-O-3 CODE	SITE
C70.0 - C70.9	Meninges
C71.0 - C71.9	Brain
C72.0 - C72.9	Central nervous system
C73.9	Thyroid
C77.0 - C77.9	Lymph nodes
C76.0 – C76.8, C80.9	Unknown and ill-defined primary sites
Multiple codes	All other sites (A single, general surgery scheme is provided for all other sites.)

#### **Definitions**

- a. <u>Definitive</u> (<u>cancer-directed</u>) <u>surgery</u> is surgery that **modifies**, **controls**, **removes**, **or destroys proliferating cancer tissue**. This includes excisional biopsy with microscopic residual disease or no residual disease. Valid codes for cancer-directed surgery of the primary site are 10-90.
- b. Non cancer-directed procedures are performed to diagnose or stage the disease (Surgical Diagnostic and Staging Procedure codes 01-07), or for relief of symptoms (Palliative Care code 1). Record Surgical Diagnostic and Staging Procedures in the designated field of the RMCDS "First Course of Treatment" screens or in item 54 on the paper abstract. The State Registry does not collect Palliative Care information.

The following procedures are examples of exploratory (diagnostic or staging) surgery (code 03 without biopsy or code 05 with biopsy).

- Celiotomy
- Laparotomy
- Cystotomy
- Nephrotomy
- Gastrotomy
- Thoracotomy, including Chamberlain procedure

The following non cancer-directed procedures are examples of bypass surgery (code 04 without biopsy or code 06 with biopsy). Code only if performed as part of the initial diagnosis and work-up. If performed for palliation only, code in *Palliative Care* if collected. The State Registry does not collect *Palliative Care*.

- Colostomy
- Nephrostomy
- Esophagostomy
- Tracheostomy
- Gastrostomy
- Urethrostomy

The following examples of diagnostic (non cancer-directed) procedures are <u>not</u> considered exploratory surgery. These procedures do not require an incision, since entry into a body cavity is made through a natural orifice. Code only if a biopsy was done as part of the procedure.

- Bronchoscopy
- Colonoscopy
- Cystoscopy
- Endoscopy
- ERCP (endoscopic retrograde cholangiopancreatography)
- Laryngoscopy
- Mediastinoscopy

 Dilatation & curettage (D & C) – Use non cancer-directed surgery code 02 when primary site is corpus uteri. Use the cancer-directed surgery code only when performed for in situ cancer of the cervix.

Brushings, washings, aspiration of cells, and hematologic findings (peripheral blood smears) are not surgical procedures.

#### Instructions

a. After determining that cancer-directed surgery was performed, use the best information in the operative and pathology reports to determine the operative procedure. The operative report title may not have adequate information for the surgery code. Use the operative report text and the pathology report to correctly identify the procedure performed. Use the information from the pathology report when an operative report is unclear or is inconsistent.

**Exception:** If the pathology report states they cannot give an accurate accounting of organs removed (tumor encasement, crush artifact, etc).

- b. In the "Surgery" field, record the site-specific 2-digit surgical code from Appendix I for the specific surgery performed as part of the first course of treatment.
   For RMCDS users, record the date the surgery was performed in the adjacent "Date" field.
- c. Record Surgical Diagnostic and Staging Procedures in the designated field of the RMCDS "First Course of Treatment" screens or in item 54 on the paper abstract. Do record all biopsies as well as cancer-directed surgical procedures.
- d. More than one cancer-directed surgical procedure can be recorded in the RMCDS "First Course of Treatment" screens or the paper abstract *Other Surgical Procedure of Primary Site* fields (Items 60 and 61).

If a biopsy was followed by a re-excision or wide excision within the first course of cancer-directed therapy and the path report for the re-excision or wide excision is negative for residual tumor, code the biopsy as an excisional biopsy. In the RMCDS program or the paper abstract, record both procedures, each with its respective date. Record the excisional biopsy date as the date of first course of treatment.

Example 1: A patient has an excisional breast biopsy at your hospital January 12, 2003. The pathology report reveals an axillary node with micrometastasis. The patient opted to have a mastectomy on March 21, 2003. Code the procedures as follows:

Item #	Surgery Code	Procedure	Date
56	41	Simple mastectomy	03/21/2003
60	22	Excisional biopsy	01/12/2003

If you can record only one surgical procedure in your system, record the surgical code with the highest priority according to the rules on the following page and use the first date on which the patient has cancer-directed surgery (41-01/12/2003).

Example 2: A patient had a breast biopsy on March 15, 2003 in the physician's office. A simple mastectomy was done at your hospital on March 27, 2003. Both procedures should be recorded, as follows:

Item #	Surgery Code	Procedure	Date
56	41	Mastectomy	03/27/2003
54	02	Incisional biopsy of primary site	03/15/2003

If you can record only one surgical procedure in your system, code surgery 41 with 03/27/2003 as the date of treatment.

- e. If the patient had <u>no surgery</u> at your hospital, but had surgery at another facility, you may enter the surgery information from the other hospital, if known. In one of the RMCDS "First Course Treatment" screen(s), record the facility ID and the appropriate surgery code and date. In the paper abstract, identify the facility in the *Description of Treatment* text field.
- f. If the patient did not have cancer-directed surgery, the reason may be recorded as instructed in the *Reason for No Surgery of Primary Site* section on page 196.

#### **Special Rules**

- a. Coding Multiple Definitive Surgeries
  - (1) If a <u>single</u> field is available for the data item *Surgical Procedure of Primary Site* or if a summary treatment field is provided and the patient has multiple cancer-directed surgeries of the primary site, code the most invasive, definitive surgery. For codes 00 through 79, the code **positions** are hierarchical. Last-listed codes take precedence over codes listed above. Use codes 80 and 90 only if more precise information about the surgery is unavailable.
    - Example: A patient has a colonoscopy with removal of a polyp in the sigmoid colon (code 28). The pathology report identifies carcinoma extending into the stalk. A week later, the patient has a hemicolectomy (code 40). Code the hemicolectomy since it is the most invasive, definitive surgery.
  - (2) If <u>multiple</u> fields are available to record consecutive surgical events, code each consecutive surgery of the primary site. For the example above, record both procedures, each with its respective date. Record the polypectomy date as the date of first course of treatment.
- b. Coding Surgery for Multiple Primaries

Code the appropriate surgery for each site when multiple primaries are excised at the same time.

- Example 1: A patient who has cancer of the cervix and of the endometrium enters your facility for a total abdominal hysterectomy. Code a total abdominal hysterectomy for <u>each</u> of the two primaries.
- Example 2: A patient has colon and skin cancer. The patient had a hemicolectomy and a wide excision of the skin lesion. Code the colectomy for colon and the wide excision for skin.
- c. If a surgical procedure removes the remaining portion of an organ that had been partially resected previously for any condition, code as total removal of the organ. If none of the primary organ remains, the code should indicate that this is the case.
  - Example 1: Resection of a stomach that had been partially excised previously is coded as total removal of stomach.
  - Example 2: Removal of a cervical stump is coded as total removal of uterus.
  - Example 3: Lobectomy of a lung with a previous wedge resection is coded as total removal of lobe.
- d. Code 98 applies to specific tumors that cannot be clearly defined in terms of primary or non-primary site. Use code 98 for the following:
  - All hematopoietic/reticuloendothelial/immunoproliferative/myeloproliferative disease sites and/or histologies, WITH or WITHOUT surgical treatment;
  - All unknown and ill-defined disease sites, WITH or WITHOUT surgical treatment.
- e. For facilities that collect *Palliative Care*: If the procedure coded in this item was provided to prolong a patient's life by controlling symptoms, to alleviate pain, or to make the patient more comfortable, then also record this surgery in the *Palliative Care* field. The State Registry does not collect *Palliative Care*.

#### 57. SURGICAL MARGINS OF THE PRIMARY SITE

Item Length: 1
Data Type: Numeric
ACoS: Required
State Registry: Optional

#### Description

This is an optional 1-character field to record a code that describes the final status of the surgical margins after resection of the primary tumor.

#### Rationale

This data item serves as a quality measure for pathology reports and is used for staging, and may be a prognostic factor in recurrence.

#### **Codes and Definitions**

0 No residual tumor All margins are grossly and microscopically negative.

Residual tumor, NOS Involvement is indicated, but not otherwise specified.

2 Microscopic residual tumor Cannot be seen by the naked eye.

3 Macroscopic residual tumor Gross tumor of the primary site which is visible to the naked eye.

7 Margins not evaluable Cannot be assessed (indeterminate).

8 No primary site surgery No surgical procedure of the primary site. Diagnosed at autopsy.

9 Unknown or not applicable It is unknown whether a surgical procedure to the primary site was

performed; death certificate-only; for lymphomas with a lymph node primary site; an unknown or ill-defined primary; or for hematopoietic, reticuloendothelial, immunoproliferative, or myeloproliferative

disease.

#### Instructions

- a. Record the margin status as it appears in the pathology report.
- b. Codes 0-3 are hierarchical. If two codes describe the margin status, use the numerically higher code.

Example: The pathology report from a colon resection describes the proximal margin as grossly involved with tumor (code 3) and the distal margin as microscopically involved (code 2). Code macroscopic involvement (code 3).

- c. If no surgery of the primary site was performed, code 8.
- d. Use code 9 for the following:
  - For lymphomas (9590-9596, 9650-9719, 9727-9729) with lymph node primary site (C77.0-C77.9);
  - For an unknown or ill-defined primary (C76.0-C76.8, C80.9):
  - For hematopoietic, reticuloendothelial, immunoproliferative, myeloproliferative, or myelodysplastic disease (C42.0, C42.1, C42.3, C42.4, or 9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989).

#### 58. SCOPE OF REGIONAL LYMPH NODE SURGERY

Item Length: 1 Data Type: Numeric ACoS: Required

State Registry: Required

#### **Description**

This item identifies the removal, biopsy, or aspiration of regional lymph node(s) at the time of surgery of the primary site or during a separate surgical event. The item can be used to compare and evaluate the extent of surgical treatment.

#### Codes

- 0 None
- 1 Biopsy or aspiration of regional lymph node, NOS
- 2 Sentinel lymph node biopsy
- 3 Number of regional nodes removed unknown or not stated; regional lymph nodes removed, NOS
- 4 1-3 regional lymph nodes removed
- 5 4 or more regional lymph nodes removed
- 6 Sentinel node biopsy and procedures that would be coded 3, 4, or 5 performed at the same time, or timing not stated
- 7 Sentinel node biopsy and procedures that would be coded 3, 4, or 5 performed at different times
- 9 Unknown or not applicable

#### **Definitions**

Code	Definition
0	No regional lymph node surgery. No lymph nodes found in the pathologic specimen. Diagnosed at autopsy.
1	Biopsy or aspiration of regional lymph node(s) regardless of the extent of involvement of disease.
2	Biopsy of the first lymph node or nodes that drain a defined area of tissue within the body. Sentinel node(s) are identified by the injection of a dye or radiolabel at the site of the primary tumor.
3	Sampling or dissection of regional lymph node(s) and the number of nodes removed is unknown or not stated. The procedure is not specified as sentinel node biopsy.
4	Sampling or dissection of regional lymph node(s) with fewer than four lymph nodes found in the specimen. The procedure is not specified as sentinel node biopsy.
5	Sampling or dissection of regional lymph nodes with at least four lymph nodes found in the specimen. The procedure is not specified as sentinel node biopsy.
6	A procedure that would be coded as 2 was performed in a single surgical event with a procedure that would be coded 3, 4, or 5. Or, a code 2 procedure and a code 3, 4, or 5 procedure were performed, but timing was not stated in the patient record.
7	A procedure that would be coded as 2 was followed in a subsequent surgical event by procedures coded as 3, 4, or 5.
9	It is unknown whether regional lymph node surgery was performed; death certificate-only; for lymphomas with a lymph node primary site; an unknown or ill-defined primary; or for hematopoietic, reticuloendothelial, immunoproliferative, or myeloproliferative disease.

#### Instructions

- a. The scope of regional lymph node surgery is collected for each surgical event even if surgery of the primary site was not performed.
- b. Record surgical procedures that aspirate, biopsy, or remove regional lymph nodes in an effort to diagnose or stage disease in this data item. Record the date of this surgical procedure in data item *Date of First Course Treatment* and/or *Date of First Surgical Procedure* as appropriate.

- c. Codes 0-7 are hierarchical. If only one procedure can be recorded, code the procedure that is numerically higher.
- d. Use code 9 for the following:
  - Primaries of the meninges, brain, spinal cord, cranial nerves, and other parts of the central nervous system (C70.0-C70.9, C71.0-C71.9, C72.0-C72.9);
  - Lymphomas (histologies 9590-9596, 9650-9719, 9727-9729) with a lymph node primary site (C77.0-C77.9);
  - Unknown or ill-defined primary (C76.0-C76.8, C80.9);
  - Hematopoietic, reticuloendothelial, immunoproliferative, myeloproliferative, or myelodysplastic disease (C42.0, C42.1, C42.3, C42.4, or histologies 9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989).
- e. Do not code *distant* lymph nodes removed during surgery to the primary site for this data item. Distant nodes are coded in the data field *Surgical Procedure/Other Site*.
- f. Refer to the current *AJCC Cancer Staging Manual* for site-specific identification of regional lymph nodes.
- g. For facilities that collect *Palliative Care*: If the procedure coded in this item was provided to prolong a patient's life by controlling symptoms, to alleviate pain, or to make the patient more comfortable, then also record this surgery in the *Palliative Care* field. The State Registry does not collect *Palliative Care*.

#### Codes with Examples:

- There was an attempt at regional lymph node dissection or sentinel lymph node dissection, but no lymph nodes were found in the pathological specimen.
- 1 Primary site is pharynx (C14.0). Aspiration of regional lymph node to confirm histology of widely metastatic disease.
- 2 Primary site is skin of back (C44.5). Histology is melanoma. A sentinel lymph node dissection was done with the removal of one lymph node. This node was negative for disease.
- 3 Primary site is prostate (C61.9). Bilateral pelvic lymph node dissection for prostate cancer.
- 6 Primary site is breast (C50.3). Sentinel lymph node biopsy of right axilla, followed by right axillary lymph node dissection during the same surgical event.
- 9 Primary site is lung (C34.9). Patient was admitted for radiation therapy following surgery for lung cancer. There is no documentation on the extent of surgery in the patient record.

#### 59. SURGICAL PROCEDURE/OTHER SITE

Item Length: 1
Data Type: Numeric
ACoS: Required

State Registry: Required

#### Description

This item records the surgical removal of distant lymph nodes or other tissue(s)/organ(s) beyond the primary site.

#### Codes

- 0 None
- 1 Nonprimary surgical procedure performed, unknown whether regional or distant
- 2 Nonprimary surgical procedure to other regional sites
- 3 Nonprimary surgical procedure to distant lymph node(s)
- 4 Nonprimary surgical procedure to distant site
- 5 Combination of codes
- 9 Unknown

#### **Definitions**

Code	Definition
0	No surgical procedure of nonprimary site was performed. Diagnosed at autopsy.
1	Nonprimary surgical resection other site(s), unknown if the site(s) is regional or distant.
2	Resection of regional site.
3	Resection of distant lymph node(s).
4	Resection of distant site.
5	Any combination of surgical procedures that would be coded 2, 3, or 4.
9	It is unknown whether any surgical procedure of a nonprimary site was performed. Death certificate only.

#### Instructions

- a. Assign the highest numbered code that describes the surgical resection of distant lymph node(s) and/or regional/distant tissue or organs.
- b. Do not code incidental removal of tissue or organs as Surgical Procedure/Other Site.
- c. Use code 1 if any surgery is performed to treat tumors of unknown or ill-defined primary sites (C76.0-C76.8, C80.9) or for hematopoietic, reticuloendothelial, immunoproliferative, myeloproliferative, or myelodysplastic disease (C42.0, C42.1, C42.3, C42.4 or 9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989).
- d. For facilities that collect *Palliative Care:* If the procedure coded in this item was provided to prolong a patient's life by controlling symptoms, to alleviate pain, or to make the patient more comfortable, then also record this surgery in the *Palliative Care* field. The State Registry does not collect *Palliative Care*.

#### Codes with Examples:

- 9 Primary site is colon (C18.1). The incidental removal of the appendix during a surgical procedure to remove a primary malignancy in the right colon.
- 1 Surgical biopsy of metastatic lesion from liver; unknown primary.
- 2 Primary site is colon (C18.3). Surgical ablation of solitary liver metastasis, hepatic flexure primary.
- 4 Primary site is rectosigmoid (C19.9). Excision of multiple liver metastasis.
- 4 Primary site is lung (C34.9). Removal of solitary brain metastasis.
- 5 Primary site is anus (C21.0). Excision of solitary liver metastasis and one large hilar lymph node.

### 60-61. OTHER SURGICAL PROCEDURE OF PRIMARY SITE (Cancer-Directed Surgery)

Item Length: 2 Data Type: Numeric ACoS: Required

State Registry: Required

#### Description

These are 2-character fields in the paper abstract to allow recording of more than one surgery performed as a part of the first course of therapy. You <u>must</u> record all procedures done at your facility, and you <u>should</u> record procedures done at other facilities, if known.

#### Instructions

- a. Complete the field(s) if more than one cancer-directed surgery is performed as a part of the first course of therapy.
- b. Complete the field(s) with the associated date(s) according to the instructions and rules provided for item 56, *Surgical Procedure of Primary Site*.

Example:

A patient has an excisional breast biopsy at your hospital January 12, 2003. The pathology report reveals an axillary node with micrometastasis. The patient opted to have a mastectomy on March 21, 2003. Code the procedures as follows:

Item #	Surgery Code	Procedure	Date
56	41	Simple mastectomy	03/21/2003
60	22	Excisional biopsy	01/12/2003

#### 62. REASON FOR NO SURGERY OF PRIMARY SITE

Item Length: 1
Data Type: Numeric
ACoS: Required

State Registry: \*Required

\*Required if available for cases diagnosed 01/01/2006 and later.

#### Description

This is an optional 1-character field for recording the reason that no surgery was performed on the primary site. This item is related only to first course of therapy. This information is to be coded if it is available in the medical record.

#### Codes

- 0 Surgery of the primary site was performed.
- Surgery of primary site was not performed because it was not part of the planned first course treatment.
- 2 Surgery of the primary site was not recommended/performed because it was contraindicated due to patient risk factors (comorbid conditions, advanced age, etc.).
- 5 Surgery of the primary site was not performed because the patient died prior to planned or recommended surgery.
- Surgery of the primary site was not performed; it was recommended by the patient's physician, but was not performed as part of the first course of therapy. No reason was noted in the patient record.
- Surgery of the primary site was not performed; it was recommended by the patient's physician, but this treatment was refused by the patient, the patient's family member, or the patient's guardian. The refusal was noted in the patient record.
- 8 Surgery of the primary site was recommended, but it is unknown if it was performed. Further followup is recommended.
- 9 It is unknown whether surgery of the primary site was recommended or performed. Diagnosed at autopsy or death certificate only.

#### Instructions

- a. If Surgical Procedure of Primary Site is coded 00, then record the reason based on documentation in the patient record.
- b. Use code zero (0) if the record specifies that surgery of the primary was performed.
- c. Use code 1 if the treatment plan offered multiple options and the patient selected treatment that did not include surgery of the primary site, or if the option of "no treatment" was accepted by the patient.
- d. Use code 1 if Surgical Procedure of Primary Site is coded 98.
- e. Use code 7 if the patient refused recommended surgical treatment, made a blanket refusal of all recommended treatment, or refused all treatment before any was recommended.
- f. Cases coded 8 should be followed and updated to a more definitive code as appropriate.
- g. Use code 9 if the treatment plan offered multiple choices, but it is unknown which treatment, if any, was provided.

#### Codes with Examples:

- 2 A patient with a primary tumor of the liver is not recommended for surgery due to advanced cirrhosis.
- 8 A patient is referred to another facility for recommended surgical resection of a gastric carcinoma, but further information from the facility to which the patient was referred is not available.

#### 63A. REGIONAL RADIATION TREATMENT MODALITY

Item Length: 2
Data Type: Numeric
ACoS: Required
State Registry: Required

#### Description

This is a required 2-character field to record the dominant modality of radiation therapy used to deliver the most clinically significant regional dose to the primary volume of interest during the first course of treatment. Record radiation delivered at your facility, as well as radiation done in any other facilities, if known.

#### **Codes and Definitions**

Codes	Label	Definition
00	No radiation treatment	Radiation therapy was not administered to the patient. Diagnosed at autopsy.
20	External beam, NOS	The treatment is known to be by external beam, but there is insufficient information to determine the specific modality.
21	Orthovoltage	External beam therapy administered using equipment with a maximum energy of less than one (1) million volts (MV). Orthovoltage energies are typically expressed in units of kilovolts (kV).
22	Cobalt-60, Cesium-137	External beam therapy using a machine containing either a Cobalt- 60 or Cesium-137 source. (Intracavitary use of these sources is coded either 50 or 51.)
23	Photons (2-5 MV)	External beam therapy using a photon producing machine with a beam energy in the range of 2-5 MV.
24	Photons (6-10 MV)	External beam therapy using a photon producing machine with a beam energy in the range of 6-10 MV.
25	Photons (11-19 MV)	External beam therapy using a photon producing machine with a beam energy in the range 11-19 MV.
26	Photons (> 19 MV)	External beam therapy using a photon producing machine with a beam energy of more than 19 MV.
27	Photons (mixed energies)	External beam therapy using more than one energy over the course of treatment.
28	Electrons	Treatment delivered by electron beam.
29	Photons and electrons mixed	Treatment delivered using a combination of photon and electron beams.
30	Neutrons, with or without photons/electrons	Treatment delivered using neutron beam.
31	IMRT	Intensity modulated radiation therapy, an external beam technique that should be clearly stated in the patient record.
32	Conformal or 3-D therapy	An external beam technique using multiple, fixed portals shaped to conform to a defined target volume. Should be clearly described as conformal or 3-D therapy in the patient record.
40	Protons	Treatment delivered using proton therapy.
41	Stereotactic radiosurgery, NOS	Treatment delivered using stereotactic radiosurgery, type not specified in the patient record.

Codes	Label	Definition
42	Linac radiosurgery	Treatment categorized as using stereotactic technique delivered with a linear accelerator.
43	Gamma Knife	Treatment categorized as using stereotactic technique delivered using a Gamma Knife machine.
50	Brachytherapy, NOS	Brachytherapy, interstitial implants, molds, seeds, needles, or intracavitary applicators of radioactive materials not otherwise specified.
51	Brachytherapy, intracavitary, LDR	Intracavitary (no direct insertion into tissues) radioisotope treatment using low dose rate applicators and isotopes (Cesium-137, Fletcher applicator).
52	Brachytherapy, intracavitary, HDR	Intracavitary (no direct insertion into tissues) radioisotope treatment using high dose rate after-loading applicators and isotopes.
53	Brachytherapy, interstitial, LDR	Interstitial (direct insertion into tissues) radioisotope treatment using low dose rate sources.
54	Brachytherapy, interstitial, HDR	Interstitial (direct insertion into tissues) radioisotope treatment using high dose rate sources.
55	Radium	Infrequently used for low dose rate (LDR) interstitial and intracavitary therapy.
60	Radioisotopes, NOS	lodine-131, Phosphorus-32, etc.
61	Strontium-89	Treatment primarily by intravenous routes for bone metastases.
62	Strontium-90	(not defined in FORDS)
80 *	Combination modality, specified *	Combination of external beam radiation and either radioactive implants or radioisotopes. *
85 *	Combination modality, NOS *	Combination of radiation treatment modalities not specified by code 80. *
98	Other, NOS	Radiation therapy administered, but the treatment modality is not specified or is unknown.
99	Unknown	It is unknown whether radiation therapy was administered. Death certificate only.

<sup>\*</sup> **Note:** For cases diagnosed prior to January 1, 2003, the codes reported in this data item describe any radiation administered to the patient as part or all of the first course of therapy. Codes 80 and 85 describe specific conversion of radiation therapy coded according to *Vol. II ROADS* and *DAM* rules and **should not** be used to record regional radiation for cases diagnosed on or later than January 1, 2003.

#### Instructions

- a. Select the code for the regional radiation treatment modality that the patient received as part of the first course of treatment.
  - (1) Radiation treatment modality will typically be found in the radiation oncologist's summary letter for the first course of treatment. Segregation of treatment components into regional and boost and determination of the respective treatment modality may require assistance from the radiation oncologist to ensure consistent coding.
  - (2) In the event multiple radiation therapy modalities were employed in the treatment of the patient, record only the dominant modality.
  - (3) Note that in some circumstances the boost treatment may precede the regional treatment.
  - (4) For purposes of this data item, photons and x-rays are equivalent.

- b. In the *Regional Radiation Treatment Modality* field, enter the code from the list above for the radiation treatment modality that the patient received.
  - For RMCDS users, record the date the radiation treatment started in a hospital-specific treatment screen in the date field adjacent to the *Radiation* item. The hospital-specific radiation item may be left blank if the facility is not continuing to collect the *ROADS Radiation* codes. *ROADS Radiation* codes are listed below for facilities that continue to record them.
- c. If only one radiation treatment modality is delivered to a patient and it is not specified as either regional or boost treatment, assume it's regional treatment and code in *Regional Radiation Treatment Modality*.

#### Codes with Examples:

- 20 A patient with prostate carcinoma receives pelvic irradiation at the reporting facility, and is then referred to a major medical center for experimental proton therapy boost.
- A patient treated with breast conserving surgery has an interstitial boost at the time of the excisional biopsy. The implant uses Ir-192 and is left in place for three days. This is followed by 6 MV photon treatment of the entire breast. In this case, the "boost" precedes the regional treatment.
- In an experimental program, a patient with as Stage III carcinoma of the prostate receives 4,500 cGy to the pelvis using 15 MV photons, and then the prostate receives a 600 cGy boost with neutrons.
- 25 Patient receives 15 MV external pelvic treatment to 4,500 cGy for cervical carcinoma, and then receives two Fletcher intracavitary implants.
- A patient with carcinoma of the parotid receives daily treatments of which 60% are delivered by 15 MV photons and 40% of the dose is delivered by 16 MV electrons.
- 99 A patient with a head and neck cancer was referred from another facility for an HDR brachytherapy boost. Detailed treatment records from the other facility are not available.

#### **ROADS** Radiation Codes (Optional)

#### Blank No radiation therapy

- Beam radiation (including all external beam sources and methods)
  (X-ray, cobalt, linear accelerator, neutron beam, betatron, spray radiation, intraoperative radiation, and stereotactic radiosurgery, such as gamma knife and proton beam, regardless of the source of the radiation.)
- 2 Radioactive implants
  (Brachytherapy, interstitial implants, molds, seeds, needles, or intracavity applicators of radioactive materials, such as cesium, radium, radon, and radioactive gold.)
- Radioisotopes
  (Internal use of radioactive isotopes, such as iodine-131, phosphorus-32, strontium 89 and 90.
  Can be given orally, intracavitarily, or by intravenous injection.)
- 4 <u>Combinations</u> of beam radiation (code 1) with radioactive implants (code 2) and/or radioisotopes (code 3)

  (The patient was treated with a combination of beam radiation and at least one of the two
  - (The patient was treated with a combination of beam radiation and at least one of the two methods described by codes 2 and 3.)
- 5 Radiation therapy, NOS (method or source not specified)
- 9 Unknown if radiation therapy recommended or performed; death certificate only cases

#### 63B. RADIATION/SURGERY SEQUENCE

Item Length: 1
Data Type: Numeric
ACoS: Required

State Registry: \*Required

\*Required if available for cases diagnosed 01/01/2006 and later.

#### Description

This is an optional 1-character field in the RMCDS abstract screen to record a code that indicates the sequencing of radiation and surgical procedures during the first course of treatment. Surgical procedures include Surgical Procedure of Primary site, Scope of Regional Lymph Node Surgery, and Surgical Procedure/Other Site.

#### Codes

- 0 No radiation therapy and/or surgical procedures; diagnosed at autopsy
- 2 Radiation therapy before surgery
- 3 Radiation therapy after surgery
- 4 Radiation therapy both before and after surgery
- 5 Intraoperative radiation therapy
- 6 Intraoperative radiation therapy with other therapy administered before or after surgery
- 9 Sequence unknown, but both surgery and radiation therapy were given; death certificate only

#### **Definitions**

Code	Definition
0	No radiation therapy given; and/or no surgery of the primary site; no scope of regional lymph node surgery; no surgery to other regional site(s), distant site(s), or distant lymph node(s); or no reconstructive surgery. Diagnosed at autopsy.
2	Radiation therapy given before surgery to primary site; scope of regional lymph node surgery; surgery to other regional site(s), distant site(s), or distant lymph node(s).
3	Radiation therapy given after surgery to primary site; scope of regional lymph node surgery; surgery to other regional site(s), distant site(s), or distant lymph node(s).
4	Radiation therapy given before and after any surgery to primary site; scope of regional lymph node surgery; surgery to other regional site(s), distant site(s), or distant lymph node(s).
5	Intraoperative therapy given during surgery to primary site; scope of regional lymph node surgery; surgery to other regional site(s), distant site(s), or distant lymph node(s).
6	Intraoperative radiation therapy given during surgery to primary site; scope of regional lymph node surgery; surgery to other regional site(s), distant site(s), or distant lymph node(s) with other radiation therapy administered before or after surgery to primary site; scope of regional lymph node surgery; surgery to other regional site(s), distant site(s), or distant lymph node(s).
9	Administration of radiation therapy and surgery to primary site; scope of regional lymph node surgery; surgery to other regional site(s), distant site(s), or distant lymph node(s) were performed and the sequence of the treatment is not stated in the patient record. It is unknown if radiation therapy was administered and/or it is unknown if surgery to primary site; scope of regional lymph node surgery; surgery to other regional site(s), distant site(s), or distant lymph node(s) were performed. Death certificate only.

#### Instructions

- a. If the patient did not receive <u>both</u> radiation therapy and surgery during the first course of therapy, record code 0. Code 0 (no radiation therapy and or surgical procedures) includes the following types of cases:
  - (1) Patients who received neither radiation therapy nor surgery;
  - (2) Patients who received radiation therapy but no surgery; and
  - (3) Patients who received surgery but were not treated with radiation therapy.

b. For patients who had both surgery <u>and</u> radiation, enter the code that describes the sequence in which the patient received radiation therapy and surgery during the first course of therapy. Code this item 2-9, as appropriate, if the patient received both radiation therapy and any one or a combination of the following surgical procedures: *Surgical Procedure of Primary Site*, *Regional Lymph Node Surgery*, or *Surgical Procedure/Other Site*.

Code in the range of 2-9 <u>only</u> if the patient had <u>both</u> surgery <u>and</u> radiation therapy as first course treatment. Surgical Diagnostic and Staging Procedures (codes 01-09) do not qualify.

# Codes with Examples:

- 0 Due to other medical conditions surgery was not performed. The patient received palliative radiation therapy to alleviate pain.
- 2 A large lung lesion was treated with radiation therapy prior to resection.
- 3 A patient received a wedge resection of a right breast mass with axillary lymph node dissection followed by radiation to right breast.
- 4 Preoperative radiation therapy was given to a large, bulky vulvar lesion and was followed by a lymph node dissection. This was then followed by radiation therapy to treat positive lymph nodes.
- 5 A cone biopsy of the cervix was followed by intracavitary implant for IIIB cervical carcinoma.
- 6 Stage IV vaginal carcinoma was treated with 5,000 cGy to the pelvis followed by a lymph node dissection and 2,500 cGy of intracavitary brachytherapy.
- An unknown primary of the head and neck was treated with surgery and radiation prior to admission, but the sequence is unknown. The patient enters for chemotherapy.

# 64A. CHEMOTHERAPY

Item Length: 2 Data Type: Numeric ACoS: Required

State Registry: Required

#### Description

This is a required 2-character field to record chemotherapy administered as first course of therapy. If chemotherapy was not administered, this item records the reason it was not administered to the patient. Chemotherapy consists of a group of anticancer drugs that inhibit the reproduction of cancer cells by interfering with DNA synthesis and mitosis.

Record chemotherapy administered at your facility, as well as chemotherapy given at any other facilities, if known.

# Codes

Blank None, chemotherapy was not part of the planned first course of therapy; diagnosed at autopsy.\*

- O1 Chemotherapy administered as first course therapy, but the type and number of agents is not documented in the patient record.
- O2 Single-agent chemotherapy administered as first course therapy.
- 03 Multiagent chemotherapy administered as first course therapy.
- 82 Chemotherapy was not recommended/administered because it was contraindicated due to patient risk factors (e.g., comorbid conditions or advanced age).
- Chemotherapy was not administered because the patient died prior to planned or recommended therapy.
- Chemotherapy was not administered. It was recommended by the patient's physician, but was not administered as part of the first course of therapy. No reason was stated in the patient record.
- Chemotherapy was not administered. It was recommended by the patient's physician, but this treatment was refused by the patient, a patient's family member, or the patient's guardian. The refusal was noted in the patient record.
- 88 Chemotherapy was recommended, but it is unknown if it was administered.
- It is unknown whether a chemotherapeutic agent(s) was recommended or administered because it is not stated in the patient record. Death certificate only.

\*Note: The code "blank" for chemotherapy in the RMCDS program is different from the code listed in the FORDS (00).

# Instructions

- a. Select the code for the type of chemotherapy that the patient received as part of the first course of treatment. Record chemotherapy as cancer-directed therapy when it is delivered concurrently or as adjuvant treatment.
  - (1) Leave the field blank if chemotherapy was not administered to the patient, and it is known that it is not usually administered for this type and stage of cancer.
  - (2) Leave the field blank if the treatment plan offered multiple options and the patient selected treatment that did not include chemotherapy.
  - (3) If it is known that chemotherapy is usually administered for this type and stage of cancer, but was not administered to the patient, use code 82, 85, 86, or 87 to record the reason it was not administered. Record the date as 00/00/0000 if one of these reason codes is used.
  - (4) Code 87 if the patient refused recommended chemotherapy, made a blanket refusal of all recommended treatment, or refused all treatment before any was recommended.
  - (5) Code 99 if it is not known whether chemotherapy is usually administered for this type and stage of cancer and there is no mention in the patient record whether it was recommended or administered. Record the date as 99/99/9999.
  - (6) If a chemotherapy drug is given for a reason other than cancer-directed treatment, do not code the drug as chemotherapy. If in doubt whether the chemotherapy drug is given to alleviate a symptom and not for cancer-directed treatment, consult your oncologist or oncology nurse.

- (7). For facilities that collect *Palliative Care*: If chemotherapy was provided to prolong a patient's life by controlling symptoms, to alleviate pain, or to make the patient more comfortable, then also record the chemotherapy provided in the *Palliative Care* field. The State Registry does not collect *Palliative Care*.
- b. In the *Chemotherapy* field, enter the code from the list above for the chemotherapy that the patient received. For RMCDS users, record the date the course of chemotherapy was started in the adjacent "Date" field.
  - Example: Single agent chemotherapy 5-FU was started on July 15, 2003 at a physician's office as part of the first course of treatment. The treatment would be entered as follows: Chemotherapy code 02, Date: 07/15/2003.
- c. One planned course of chemotherapy may be given in several segments. These segments are recorded as <u>one</u> course. The date listed for that course of chemotherapy should be the date the first segment of that course began.
- d. Two or more single agents given at separate times during the first course of cancer-directed therapy are considered a combination regimen and coded 3 (chemotherapy, multiple agents). If two or more single agents are given at different times after the first course, it is subsequent treatment and can be recorded in the "Subsequent Treatment" RMCDS screens. The State Registry does not collect subsequent treatment.

# **Chemotherapy Information and Definitions**

- a. Refer to the SEER Program Self-Instructional Manual for Tumor Registrars, Book Eight, Antineoplastic Drugs, Third Edition, 1994, for drug categories or if in doubt as to which drugs are coded to this field.
- Chemotherapeutic agents may be administered by intravenous infusion or given orally. Other methods of administration include:
  - *Intrathecal.* Administered directly into the cerebrospinal fluid through a lumbar puncture needle into an implanted access device (Ommaya reservoir).
  - **Pleural/pericardial.** Injected directly into pleural or pericardial space to control malignant effusions. **Intraperitoneal.** Injected into the peritoneal cavity.
  - Hepatic artery. Injected into a catheter inserted into the artery that supplies blood to the liver.
- c. Chemotherapy agents may be administered singly or in a combination regimen of two or more chemotherapy drugs. They are administered in treatment cycles. The time span of a treatment cycle varies. It is dependent upon the histology, stage of disease, and treatment modalities. Chemotherapy may be administered for several weeks or several years.
- d. Clarification of terms:
  - (1) **Concurrent chemotherapy** (multimodality therapy, combined modality therapy) is given before, during, or after other treatment modalities (surgery, radiation, etc.) as part of the treatment plan.
  - (2) **Adjuvant chemotherapy** is given after other methods have destroyed the clinically detectable cancer cells. Chemotherapy is given to destroy micrometastases (undetectable cancer cells). The intent is to prevent or delay a recurrence.
    - Example: A patient has breast cancer with positive nodes. All detectable tumor is removed by a modified radical mastectomy. The patient receives adjuvant chemotherapy to destroy any micrometastasis that may be present. The chemotherapy is given to delay or prevent a recurrence.
  - (3) **Neoadjuvant therapy** is given prior to surgical resection or radiation therapy to reduce the bulk of a locally advanced primary cancer.
    - Example: A patient with locally advanced breast cancer receives chemotherapy to reduce tumor size. Chemotherapy is followed by a modified radical mastectomy.

(4) Ancillary drugs are medications whose actions are not directed at the patient's malignancy per se but that enhance the effects of the cancer-directed therapy. For example, ancillary drugs may modulate the actions of specific chemotherapeutic agents by increasing their effectiveness in destroying tumor cells or by decreasing the potential for specific side effects. Ancillary drugs are not to be coded as cancer-directed therapy.

Example: Folinic acid (leucovorin) stabilizes the drug-enzyme complex and thus increases the cytotoxic effects of 5-FU and is frequently administered with 5-FU for this purpose.

e. Chemotherapy is divided into the following classifications:

Group	Subgroup(s)	Examples
Alkylating agents	Nitrogen mustard	Mechlorethamine (Mustargen), phenylalanine mustard (Melphalan), chlorambucil (Leukeran), cyclophosphamide (Cytoxan)
	Ethylenimine derivatives	Triethylene-thiophosphoramide (Thio-TEPA)
	Alkyl sulfonates	Busulfan (Myleran)
	Nitrosoureas	Carmustine (Lomustine)
	Triazines	DTIC (Dacarbazine)
Antimetabolites	Folic acid analogs	Methotrexate (Amethopterin, MTX)
	Pyrimidine analogs	5-fluorouracil (5-FU)
	Purine analogs	6-mercaptopurine (6-MP)
Natural products	Antitumor antibiotics	Dactinomycin (Actinomycin D), doxorubicin (Adriamycin), daunorubicin (Daunomycin), bleomycin (Blenoxane), mitomycin C (Mutamycin)
	Plant alkaloids	Vinblastine (VBL, Velban), vincristine (VCR, Oncovin)
	Enzymes	L-Asparaginase (Elspar)
Miscellaneous agents		Cis-diammine dichloroplatinum II (Cisplatin), hydroxyurea (Hydrea), procarbazine (Matulane)

f. If the patient has an adverse reaction, the physician may change one of the drugs in a combination regimen. If the replacement drug belongs to the same group as the original drug, there is no change in the regimen.

Example: The physician documents a multimodality treatment plan that includes a combination regimen of chemotherapy. Velban is one of the drugs in the chemotherapy regimen. After two cycles of chemotherapy, the physician says the Velban will be replaced with Oncovin and the chemotherapy will continue as planned. This is a continuation of the planned first course of therapy.

If the replacement drug is in a different group than the original drug, it is subsequent therapy.

**Exception:** Unless there is disease progression, neoadjuvant chemotherapy and all subsequent planned first course of treatment would be recorded as first course, even if there is a change in chemotherapeutic agents and/or groups.

# 64B. SYSTEMIC/SURGERY SEQUENCE

Item Length: 1
Data Type: Numeric
ACoS: Required
State Registry: Required\*

\*Required for cases diagnosed 01/01/2006 and later.

# Description

This is a required 1-character field in the RMCDS abstract screen to record a code that indicates the sequencing of systemic therapy and surgical procedures provided as part of the first course of treatment. Surgical procedures include Surgical Procedure of Primary Site, Scope of Regional Lymph Node Surgery, and Surgical Procedure/Other Site.

# Codes

- 0 No systemic therapy and/or surgical procedures; diagnosed at autopsy
- 2 Systemic therapy before surgery
- 3 Systemic therapy after surgery
- 4 Systemic therapy both before and after surgery
- 5 Intraoperative systemic therapy
- 6 Intraoperative systemic therapy with other therapy administered before or after surgery
- 9 Sequence unknown, but both surgery and systemic therapy were given; death certificate only

#### **Definitions**

Code	Definition
0	No systemic therapy was given; and/or no surgery of primary site; no scope of regional lymph node surgery; no surgery to other regional site(s), distant site(s), or distant lymph node(s); or no reconstructive surgery was performed. Diagnosed at autopsy.
2	Systemic therapy was given before surgery of primary site; scope of regional lymph node surgery; surgery to other regional site(s), distant site(s), or distant lymph node(s) was performed.
3	Systemic therapy was given after surgery of primary site; scope of regional lymph node surgery; surgery to other regional site(s), distant site(s), or distant lymph node(s) was performed.
4	Systemic therapy was given before and after any surgery of primary site; scope of regional lymph node surgery; surgery to other regional site(s), distant site(s), or distant lymph node(s) was performed.
5	Intraoperative systemic therapy was given during surgery of primary site; scope of regional lymph node surgery; surgery to other regional site(s), distant site(s), or distant lymph node(s).
6	Intraoperative systemic therapy was given during surgery of primary site; scope of regional lymph node surgery; surgery to other regional site(s), distant site(s), or distant lymph node(s) with other systemic therapy administered before or after surgery of primary site; scope of regional lymph node surgery; surgery to other regional site(s), distant site(s), or distant lymph node(s) was performed.
9	Administration of systemic therapy and surgery of primary site; scope of regional lymph node surgery; surgery to other regional site(s), distant site(s), or distant lymph node(s) were performed and the sequence of the treatment is not stated in the patient record. It is unknown if systemic therapy was administered and/or it is unknown if surgery of primary site; scope of regional lymph node surgery; surgery to other regional site(s), distant site(s), or distant lymph node(s) were performed. Death certificate only.

# Instructions

- a. Systemic/Surgery Sequence is to be used for patients diagnosed on or after January 1, 2006.
- b. Code the administration of systemic therapy in sequence with the first surgery performed.

- c. If none of the following surgical procedures was performed: Surgical Procedure of Primary Site, Scope of Regional Lymph Node Surgery, and Surgical Procedure/Other Site, then this item should be coded 0.
- d. If the patient received both systemic therapy and any on or a combination of the following surgical procedures: Surgical Procedure of Primary Site, Scope of Regional Lymph Node Surgery, and Surgical Procedure/Other Site, then code this item 2-6, as appropriate.

#### Codes with Examples:

- 0 Due to other medical conditions surgery was not performed. The patient refused other treatment.
- O A patient with lobular carcinoma in situ of the breast underwent an excisional biopsy. No chemotherapy was recommended.
- O A patient with small cell carcinoma of the lung was treated with VP-16 and carboplatin.
- 2 A patient with prostate cancer received hormone therapy prior to a radical prostatectomy.
- 3 A patient underwent a colon resection followed by a 5-FU based chemotherapy regimen.
- 4 A patient with breast cancer receives pre-operative chemotherapy followed by post-operative Tamoxifen.
- 5 A patient with an intracranial primary undergoes surgery at which time a glial wafer in implanted into the resected cavity.
- 6 A patient with metastatic colon cancer receives intraoperative chemotherapy to the liver.
- An unknown primary of the head and neck was treated with surgery and chemotherapy prior to admission, but the sequence is unknown. The patient enters for radiation therapy.

# 64C. DATE SYSTEMIC THERAPY STARTED

Item Length: 8
Data Type: Numeric
ACoS: Required

State Registry: Required

# Description

This is a required 8-character field for recording the date of initiation for systemic therapy that is part of the first course of treatment. Systemic therapy includes the administration of chemotherapy agents, hormonal agents, biological response modifiers, bone marrow transplants, stem cell harvest, and surgical and/or radiation endocrine therapy.

# Codes

	<u>Month</u>	<u>Day</u>	Year
00		00	0000
01	January	01	Use four-digit year (e.g., 2006)
02	February	02	9999 Year unknown
03	March	03	
04	April	•••	
05	May	***	
06	June	25	
07	July	26	
80	August	***	
09	September	30	
10	October	31	
11	November	99 Day unknow	n
12	December		
99	Month unknown		

# **Special Codes**

00000000	No systemic therapy was administered. Diagnosed at autopsy.
8888888	Systemic therapy is planned as part of the first course of therapy, but had not been started
	at the time of the most recent follow-up. The date should be revised at the next follow-up.
99999999	It is unknown if any systemic therapy was administered; the date is unknown; or the case
	was identified by death certificate only.

#### Instructions

- a. Record the first or earliest date on which systemic therapy was administered. Systemic therapy includes *Chemotherapy, Hormone Therapy, Immunotherapy,* and *Hematologic Transplant and Endocrine Procedures*.
- b. Record the month, day, and year (MM/DD/YYYY) the systemic therapy was started. Fill in with leading zeros where needed. For example, record June 3, 2006 as 06/03/2006.
- c. If the exact date of the beginning of systemic therapy is not available, record an approximate date. If information is limited to a description, use the following:

DESCRIPTIVE TERM USED	DATE CODE
Spring	April
The middle of the year	July
Fall	October
Winter	Try to determine if this means the beginning of the year (January) or the end of the year (December). Code as indicated.

d. Do <u>not</u> record the date of initiation of *Other Treatment* in this field, even if it is the only treatment administered.

Examples: 12152005	A patient with beast cancer begins her regimen of chemotherapy on December 15, 2005, and is subsequently given tamoxifen on January 20, 2006.
06222006	A patient with Stage IV prostate cancer has an orchiectomy on June 2, 2006. The patient is then started on a regime of hormonal agents on June 9, 2006.
09992006	If the exact date of the beginning of treatment is not available, record an approximate date. For example, September 2006.
04992006	The information is limited to the description "Spring" of 2006.
07992006	The information is limited to the description "The middle of the year," 2006.
10992006	The information is limited the description "Fall" of 2006.
12992005 or 01992006	The information is limited to the description "Winter." Try to determine if this means the beginning or the end of the year. Code January or December as indicated.

# 65. HORMONE THERAPY (HORMONE/STEROID [ENDOCRINE] THERAPY)

Item Length: 2
Data Type: Numeric
ACoS: Required
State Registry: Required

# Description

This is a required 2-character field to record hormone or steroid (endocrine) therapy administered as part of the first course of treatment. If hormone therapy was not administered, this item records the reason it was not administered. Hormone therapy consists of a group of drugs that may affect the long-term control of a cancer's growth and includes hormones, antihormones, and steroids.

Record hormone therapy administered at your facility, as well as hormone therapy given in any other facilities, if known.

#### Codes

Blank None; hormone therapy was not part of the planned first course of therapy; diagnosed at autopsy.\*

- 01 Hormone therapy administered as first course therapy.
- Hormone therapy was not recommended/administered because it was contraindicated due to patient risk factors (e.g., comorbid conditions or advanced age).
- Hormone therapy was not administered because the patient died prior to planned or recommended therapy.
- Hormone therapy was not administered. It was recommended by the patient's physician, but was not administered as part of the first course of therapy. No reason was stated in the patient record.
- Hormone therapy was not administered. It was recommended by the patient's physician, but this treatment was refused by the patient, a patient's family member, or the patient's guardian. The refusal was noted in the patient record.
- 88 Hormone therapy was recommended, but it is unknown if it was administered.
- 99 If is unknown whether a hormonal agent(s) was recommended or administered because it is not stated in the patient record. Death certificate only.

\***Note:** The code "blank" for hormone therapy in the RMCDS program is different from the code listed in the *FORDS* (00)

#### **Definitions**

- a. Hormones promote hormonal withdrawal or hormonal interface to alter the growth of cancer. Hormone therapy may effect a long-term control of the cancer growth. It is not usually used as a curative measure. Hormone classifications are:
  - Estrogen (DES [diethylstilbestrol])
  - Progestins (Provera, Megace)
  - Androgens (Halotestin)
  - Adrenocorticosteroids (Prednisone, Decadron)
  - Other agents:

Antiestrogens (Tamoxifen, Nolvadex, Arimidex, Aromasin, Faslodex, Fareston)

Hormone synthesis inhibitors (Elipten, Cytadren)

Gonadotropin releasing hormones (Lupron, Viadur)

Thyroid hormones (Cytomel)

- b. Refer to the SEER Program Self-Instructional Manual for Tumor Registrars, Book Eight, Antineoplastic Drugs, Third Edition, 1994 if in doubt as to which drugs are coded to this field. For example, leuprolide and flutamide are both agents acting through hormonal mechanisms and should be coded as hormones.
- c. Adrenocorticotropic hormones (cancer-directed only) are coded for leukemias, lymphomas, multiple myelomas, breast, and prostate cancer.

#### Instructions

- a. Record code 01 if the patient received hormone therapy as part of the first course of treatment. Administration of hormones or antihormones (cancer-directed only) should be recorded for all primary and metastatic sites.
  - (1) Record prednisone as hormonal therapy when administered in combination with chemotherapy, such as MOPP (mechlorethamine, vincristine, procarbazine, prednisone) or COPP (cyclophosphamide, vincristine, procarbazine, prednisone).
  - (2) Code 01 for thyroid replacement therapy that inhibits TSH (thyroid-stimulating hormone). TSH is a product of the pituitary gland that can stimulate tumor growth.
  - (3) Do not code hormone drugs as hormone therapy when administered for reasons other than chemotherapeutic treatment. Examples:
    - Hormone drug used to alleviate symptoms (e.g., Solu-Medrol used to control vomiting; Decadron to reduce edema and relieve neurological symptoms from brain metastasis in a lung primary.) Do not code as hormone therapy.
    - Hormone replacement therapy used when tumor involvement or cancer-directed treatment has destroyed hormone-producing tissue. Do not code as hormone therapy.
  - (4) For facilities that collect *Palliative Care*: If hormone therapy was provided to prolong a patient's life by controlling symptoms, to alleviate pain, or to make the patient more comfortable, then also record the hormone therapy provided in the *Palliative Care* field. The State Registry does not collect *Palliative Care*.
- b. Leave the field blank:
  - (1) If hormone therapy was not administered to the patient, and it is known that it is not usually administered for this type and stage of cancer;
  - (2) If the treatment plan offered multiple options, and the patient selected treatment that did not include hormone therapy.
- c. If it is known that hormone therapy is usually administered for this type and stage of cancer, but was not administered to the patient, use code 82, 85, 86, or 87 to record the reason it was not administered. Record the date as 00/00/0000 if one of these reason codes is used.
- d. Code 87 if the patient refused recommended hormone therapy, made a blanket refusal of all recommended treatment, or refused all treatment before any was recommended.
- e. Code 99 if it is not known whether hormone therapy is usually administered for this type and stage of cancer, and there is no mention in the patient record whether it was recommended or administered. Record the date as 99/99/9999.
- f. In the *Hormone Therapy* field, record 01 for hormone therapy. For RMCDS users, record the date the course of hormone therapy was started in the adjacent "Date" field.
  - Example: Tamoxifen was started on July 15, 2003. The treatment would be entered as follows: Hormone Therapy code 01, Date: 07/15/2003.

# Codes with Examples:

- blank A patient has advanced lung cancer with multiple metastases to the brain. The physician orders Decadron to reduce the edema in the brain and relieve the neurological symptoms. Decadron is not coded as hormonal therapy.
- blank A patient with breast cancer may be treated with aminoglutethimide (Cytadren, Elipten), which suppresses the production of glucocorticoids and mineralocorticoids. This patient must take glucocorticoid (hydrocortisone) and may also need a mineralocorticoid (Florinef) as a replacement therapy.
- blank A patient with advanced disease is given prednisone to stimulate the appetite and improve nutritional status. Prednisone is not coded as hormone therapy.
- 01 A patient with metastatic prostate cancer is administered flutamide (an antiestrogen).
- A patient with metastatic prostate cancer declines the administration of Megace (a progestational agent) and the refusal is noted in the patient record.

66. IMMUNOTHERAPY
(BIOLOGICAL RESPONSE MODIFIER [BRM] THERAPY)

Item Length: 2
Data Type: Numeric
ACoS: Required

State Registry: Required

# Description

This is a required 2-character field to record immunotherapy or Biological Response Modifier (BRM) therapy administered as part of the first course of treatment. Record immunotherapy administered at your facility, as well as immunotherapy given in any other facilities, if known.

#### Codes

blank None; immunotherapy was not part of the planned first course of therapy; diagnosed at autopsy.\*

- 01 Immunotherapy administered as first course therapy.
- 82 Immunotherapy was not recommended/administered because it was contraindicated due to patient risk factors (e.g., comorbid conditions or advanced age).
- Immunotherapy was not administered because the patient died prior to planned or recommended therapy.
- lmmunotherapy was not administered. It was recommended by the patient's physician, but was not administered as part of the first course of therapy. No reason was stated in the patient record.
- Immunotherapy was not administered. It was recommended by the patient's physician, but this treatment was refused by the patient, a patient's family member, or the patient's guardian. The refusal was noted in the patient record.
- 88 Immunotherapy was recommended, but it is unknown if it was administered.
- 99 It is unknown whether an immunotherapeutic agent(s) was recommended or administered because it is not stated in the patient record. Death certificate only.

\*Note: The code "blank" for immunotherapy in the RMCDS program is different from the code listed in the *FORDS* (00).

# **Definitions**

- a. Immunotherapy (BRM) consists of biological or chemical agents that alter the immune system or change the host's response (defense mechanism) to the tumor cells.
- b. Examples of immunotherapy (BRM) agents are:

Aldara

Allogenic cells

BCG vaccine

Campath

C-ParvumHerceptin

Interferon

Levamisole

Monoclonal antibodies

MVE-2

Oncaspar

Ontak

Pyran copolymer

■ 13-CIS Vitamin A Acid

Targretin

Thymosin

■ TNF (Tumor Necrosis Factor)

Vaccine therapy

Virus therapy

■ Vitamin A

Vitamin therapy

c. Refer to the SEER Program Self-Instructional Manual for Tumor Registrars, Book Eight, Antineoplastic Drugs, Third Edition, 1994 if in doubt as to which drugs are coded to this field.

#### Instructions

- a. Record code 01 if immunotherapy (BRM) was administered and determine the date it was started.
- b. Leave the field blank:

If immunotherapy was not administered to the patient, and it is known that it is not usually administered for this type and stage of cancer:

If the treatment plan offered multiple options, and the patient selected treatment that did not include immunotherapy.

- c. If it is known that immunotherapy is usually administered for this type and stage of cancer, but was not administered to the patient, use code 82, 85, 86, or 87 to record the reason it was not administered. Record the date as 00/00/0000 if one of these reason codes is used.
- d. Code 87 if the patient refused recommended immunotherapy, made a blanket refusal of all recommended treatment, or refused all treatment before any was recommended.
- e. Code 99 if it is not known whether immunotherapy is usually administered for this type and stage of cancer, and there is no mention in the patient record whether is was recommended or administered. Record the date as 99/99/9999.
- f. In the *Immunotherapy* field, record code 01 for immunotherapy (BRM). For RMCDS users, record the date the course of immunotherapy was started in the adjacent "Date" field.

Example: Interferon was started on July 15, 2003. The treatment would be entered as follows: Immunotherapy code 01, Date: 07/15/2003.

For facilities that collect *Palliative Care*: If immunotherapy was provided to prolong a patient's life by controlling symptoms, to alleviate pain, or to make the patient more comfortable, then also record the immunotherapy provided in the *Palliative Care* field. The State Registry does not collect *Palliative Care*.

# 67. HEMATOLOGIC TRANSPLANT AND ENDOCRINE PROCEDURE

Item Length: 2
Data Type: Numeric
ACoS: Required

State Registry: Required

# Description

This is a required 2-character field to record any systemic therapeutic *procedures* administered as part of the first course of treatment at this and all other facilities. These include bone marrow transplants, stem cell harvests, surgical and/or radiation endocrine therapy. If none of these *procedures* were administered, then use this field to record the reason they were not performed.

#### Rationale

This data item allows the evaluation of patterns of treatment that involve the alteration of the immune system or change the patient's response to tumor cells but does not involve the administration of anti-neoplastic agents. In addition, when evaluating the quality of care, it is useful to know the reason if these procedures were not performed.

#### Codes

- blank No transplant procedure or endocrine therapy was administered as part of first course therapy; diagnosed at autopsy.\*
- 10 A bone marrow transplant procedure was administered, but the type was not specified.
- 11 Bone marrow transplant autologous.
- 12 Bone marrow transplant allogeneic.
- 20 Stem cell harvest and infusion.
- 30 Endocrine surgery and/or endocrine radiation therapy.
- 40 Combination of endocrine surgery and/or radiation with a transplant procedure. (Combination of codes 30 and 10, 11, 12, or 20.)
- Hematologic transplant and/or endocrine surgery/radiation was not recommended/administered because it was contraindicated due to patient risk factors (e.g., comorbid conditions or advanced age).
- Hematologic transplant and/or endocrine surgery/radiation was not administered because the patient died prior to planned or recommended therapy.
- Hematologic transplant and/or endocrine surgery/radiation was not administered. It was recommended by the patient's physician, but was not administered as part of the first course of therapy. No reason was stated in the patient record.
- Hematologic transplant and/or endocrine surgery/radiation was not administered. It was recommended by the patient's physician, but this treatment was refused by the patient, a patient's family member, or the patient's guardian. The refusal was noted in the patient record.
- Hematologic transplant and/or endocrine surgery/radiation was recommended, but it is unknown if it was administered.
- 99 It is unknown whether hematologic transplant and/or endocrine surgery/radiation was recommended or administered because it is not stated in the patient record. Death certificate only.

\*Note: The code "blank" for hematologic transplant and endocrine procedures in the RMCDS program is different from the code listed in the FORDS (00).

#### **Definitions**

- a. Bone marrow transplants should be coded as either autologous (bone marrow originally taken from the patient) or allogeneic (bone marrow donated by a person other than the patient). For cases in which the bone marrow transplant was syngeneic (transplanted marrow from an identical twin), the item is coded as allogeneic.
- b. Stem cell harvests involve the collection of immature blood cells from the patient and the reintroduction by transfusion of the harvested cells following chemotherapy or radiation therapy.
- c. Endocrine irradiation and/or endocrine surgery are procedures that suppress the naturally occurring hormonal activity of the patient and thus alter or effect the long-term control of the cancer's growth.

These procedures must be bilateral to qualify as endocrine surgery or endocrine radiation. If only one gland is intact at the start of treatment, surgery and/or radiation to that remaining gland qualifies as endocrine surgery or endocrine radiation.

#### Instructions

- a. Select the code for the type of procedure the patient received and determine the date it was performed.
  - (1) Leave the field blank if a transplant or endocrine procedure was not administered to the patient and it is known that these procedures are not usually administered for this type and stage of cancer.
  - (2) Leave the field blank if the treatment plan offered multiple options and the patient selected treatment that did not include a transplant or endocrine procedure.
  - (3) If it is known that a transplant or endocrine procedure is usually administered for this type and stage of cancer, but was not administered to the patient, use code 82, 85, 86, or 87 to record the reason it was not administered. Record the date as 00/00/0000 if one of these reason codes is used.
  - (4) Code 87 if the patient refused a recommended transplant or endocrine procedure, or made a blanket refusal of all recommended treatment, or refused all treatment before any was recommended.
  - (5) Code 99 if it is not known whether a transplant or endocrine procedure is usually administered for this type and stage of cancer and there is no mention in the patient record whether is was recommended or administered. Record the date as 99/99/9999.
- b. In the *Hematologic Transplant and Endocrine Procedure* field, enter the code from the list above for the procedure that the patient received. For RMCDS users, record the date the procedure was performed in the adjacent "Date" field.

For facilities that collect *Palliative Care*: If the hematologic transplant or endocrine procedure coded in this item was provided to prolong a patient's life by controlling symptoms, to alleviate pain, or to make the patient more comfortable, then also record the procedure provided in the *Palliative Care* field. The State Registry does not collect *Palliative Care*.

# 68. OTHER TREATMENT Item Length: 1 Data Type: Numeric ACoS: Required State Registry: Required

# **Description**

This is a required 1-character field to record cancer-directed treatment that cannot be defined as surgery, radiation, or systemic therapy according to the defined data items in this manual. Record the therapy delivered at your facility, as well as other therapy given in any other facilities, if known.

Codes and Definitions			
Codes	Label	Definition	
blank*	None	All cancer treatment was coded in other treatment fields (surgery, radiation, systemic therapy). Patient received no cancer treatment. Diagnosed at autopsy.	
1	Other	Cancer treatment that cannot be appropriately assigned to specified treatment data items (surgery, radiation, systemic).  Examples: Arterial block for renal cell carcinoma Hyperbaric oxygen (as adjunct to cancer-directed treatment) Hyperthermia Use this code for treatment unique to hematopoietic diseases (see Notes below).	
2	Other – Experimental	This code is not defined. It may be used to record participation in institution-based clinical trials.	
3	Other – Double Blind	A patient is involved in a double-blind clinical trial. Code the treatment actually administered when the double-blind trial code is broken.	
6	Other – Unproven	Cancer treatments administered by nonmedical personnel.	
		Unproven therapy includes unproven methods of cancer management that are, as defined by the Board of Directors of the American Cancer Society, Inc. in 1981: "Those diagnostic tests or therapeutic modalities that are promoted for cancer prevention, diagnosis or treatment and that are, on the basis of careful review by scientists and/or clinicians, not deemed proven nor recommended for current use."	
7	Refusal	Other treatment was not administered. It was recommended by the patient's physician, but this treatment (which would have been coded 1, 2, or 3) was refused by the patient, a patient's family member, or the patient's guardian. The refusal was noted in the patient record.	
8	Recommended; unknown if administered	Other treatment was recommended, but it is unknown whether it was administered.	
9	Unknown	It is unknown whether other treatment was recommended or administered, and there is no information in the medical record to confirm the recommendation or administration of other treatment. Death certificate only.	

<sup>\*</sup>The code "blank" for other therapy in the RMCDS program is different from the code listed in the *FORDS* (0).

#### Note:

Treatment for reportable hematopoietic diseases can include supportive care, observation, or any treatment that does not meet the usual definition in which treatment "modifies, controls, removes, or destroys proliferating cancer tissue." Supportive care and observation are not recorded in this data item, but for certain hematopoietic diseases treatments such as phlebotomy, transfusions, and aspirin are defined below and should be coded 1.

- Phlebotomy may be called blood removal, blood letting, or venisection.
- Transfusions may include whole blood, RBCs, platelets, plateletpheresis, fresh frozen plasma (FFP), plasmapheresis, and cryoprecipitate.
- Aspirin (also known as ASA, acetylsalicylic acid, or by a brand name) is used as a treatment for
  essential thrombocythemia. Record ONLY aspirin therapy to thin the blood for symptomatic control of
  thrombocythemia. To determine whether aspirin is administered for pain, cardiovascular protection, or
  thinning of platelets in the blood, use the following general guideline:
  - Pain control is approximately 325-1000 mg every 3-4 hours.
  - Cardiovascular protection starts at about 160 mg/day.
  - Aspirin treatment for essential thrombocythemia is low dose, approximately 70-100 mg/day.

#### Instructions

- a. Select the code for other treatment received by the patient as part of the first course of treatment.
- b. In the *Other Treatment* field, enter the code from the list above for the "other" therapy that the patient received. For RMCDS users, record the date the course of other therapy was started in the adjacent "Date" field.

For facilities that collect *Palliative Care*: If other treatment was provided to prolong a patient's life by controlling symptoms, to alleviate pain, or to make the patient more comfortable, then also record the other treatment administered in the *Palliative Care* field. The State Registry does not collect *Palliative Care*.

- c. If other therapy was recommended (code 8) or refused (code 7), record the appropriate code in *Other Treatment*. Use 99/99/9999 for the date if recommended and unknown if administered. Use 00/00/0000 for the date if recommended and refused.
- d. When an unproven therapy, such as laetrile, is the first course of therapy, the date that the patient started taking that therapy is the date that therapy was initiated.
- e. Do not code ancillary drugs (defined in the chemotherapy section, p. 203) in this field. There is no coding scheme for ancillary drugs.

Examples of ancillary drugs:

Allopurinol
G-CSF (growth stimulating factors)
Epogen
Leucovorin

Neupogen

This a partial list. Refer to the SEER Program Self-Instructional Manual for Tumor Registrars, Book Eight, Antineoplastic Drugs, Third Edition, 1994 if in doubt as to which drugs are ancillary drugs and not coded.

# 69. DESCRIPTION OF TREATMENT

Data Type: Text ACoS: N/A

State Registry: Required

# Description

This is a required text field for recording a narrative description of all treatment given for the tumor being reported, whether treatment is to the primary or metastatic site. In the paper abstract, the *Description of Treatment* field is a single field for recording all types of treatment. The RMCDS abstract screen provides a separate text field for each treatment modality. Facilities using other types of registry software should follow their vendor's instructions for recording treatment text.

#### Rationale

Text is needed to justify the codes selected for the data items and to record information that is not coded at all. The text is used for quality control and special studies.

# Instructions

# Surgical Procedures

- a. Record information describing all surgical procedures performed as part of treatment.
- b. Include, as applicable: Date of each procedure; facility where each procedure was performed; type(s) of surgical procedure(s), including excisional biopsies and surgery to other and distant sites; lymph nodes removed; regional tissues removed; metastatic sites; and positive and negative findings.

# Radiation Beam

- a. Record information regarding treatment of the tumor with beam radiation.
- b. Include, as applicable: Date radiation treatment began; facility where treatment was given; type(s) of beam radiation (e.g., orthovoltage, cobalt 60, MV x-rays, electrons, mixed modalities); and other treatment information (e.g., patient discontinued after five treatments).

# Radiation Other

- a. Record information regarding treatment of the tumor with radiation other than beam radiation. This includes brachytherapy and systemic radiation therapy.
- b. Include, as applicable: Date treatment began; facility where treatment was given; type(s) of non-beam radiation (e.g., high dose rate brachytherapy, seed implant, radioisotopes [I-131]); and other treatment information.

# Chemotherapy

- a. Record information regarding chemotherapy treatment of the tumor.
- b. Include, as applicable: Date chemotherapy began; facility where chemotherapy was given; type of chemotherapy (e.g., name of agent(s) or protocol); and other treatment information (e.g., treatment cycle incomplete).

# **Hormone**

- a. Record information about hormonal cancer-directed treatment.
- b. Include, as applicable: Date treatment began; facility where treatment was given; type of hormone or antihormone agent(s) (e.g., Tamoxifen); type of endocrine surgery or radiation (e.g., orchiectomy); and other treatment information (e.g., treatment cycle incomplete).

# Immunotherapy/BRM

- Record information regarding the treatment of the tumor with biological response modifiers or immunotherapy.
- b. Include, as applicable: Date treatment began; facility where treatment was given; type of BRM agent (e.g., Interferon, BCG); BRM procedures (e.g., bone marrow transplant, stem cell transplant); and other treatment information (e.g., treatment cycle incomplete).

# Other Treatment

a. Record information treatment that cannot be defined as one of the other treatment modalities. This includes experimental and blinded clinical trials.

b. Include, as applicable: Date treatment began; facility where treatment was given; type of treatment (e.g., blinded clinical trial, hyperthermia); and other treatment information (e.g., treatment cycle incomplete).

# 70. DATE OF LAST CONTACT OR DEATH

Item Length: 8
Data Type: Numeric
ACoS: Required
State Registry: Required

# Description

This is a required 8-character field to record the date of last contact (DLC). If the patient is dead, this field records the date of death. Record month, day, and year (MM-DD-YYYY), entering leading zeros when necessary.

Example: The patient died on June 1, 2003. This would be entered as 06/01/2003.

#### Definition

This date may be the discharge date, date of death, date of a patient's visit to a doctor's office or clinic, or the date the patient was last contacted, whichever is the most recent. This date must be the latest date in the record. For example, a treatment date cannot be later than the *Date of Last Contact*.

#### Instructions

- a. If no information is known after the patient is discharged from your hospital, record the date of discharge or the date of the patient's last outpatient visit. When abstracting a case with more than one admission or clinic visit, make sure the date of last contact is the last clinic visit date or the last discharge date, or whatever the latest date is.
- b. If you are aware of a more recent date the patient was last alive after discharge (such as through correspondence or telephone contact), record the latest date of contact known. The date may be the date the patient was contacted by telephone or responded to a letter. Record the date of the actual patient contact. Do not use the date information was received in the mail, or the date information was requested from a patient, physician, or clinic. Do not record the date follow-up information was recorded on the abstract or follow-up card, or the date the case was entered into the computer.
- c. If a patient has multiple primaries, all records should have the same date of last contact. If the State Cancer Registry receives information from more than one facility for the same patient, this field will be updated in each of the patient's records. The latest date of last contact or death will be recorded for all of the patient's tumors.
- d. Estimate the date of last contact when the exact date is not available. An approximate date is better than using unknowns.

If the specific day of the month is unknown, record 99 in the day section (third and fourth spaces).

e. If information is limited to a description, use the following:

DESCRIPTIVE TERM USED	DATE CODE
Spring	April
The middle of the year	July
Fall	October
Winter	Try to determine if this means the beginning of the year (January) or the end of the year (December). Code as indicated.

f. A blank or unknown date (99/99/9999) in this field will result in a computer error message. You must know some date the patient was last seen, even if it is the day they were last seen at your hospital.

The Vital Status and Cancer Status fields below relate to this date.

# 71. VITAL STATUS (STATUS OF PATIENT)

Item Length: 1
Data Type: Numeric
ACoS: Required
State Registry: Required

# Description

This is a required 1-character field to record a code that indicates patient's vital status (dead or alive) as of the *Date of Last Contact (or Death)*. Use the most accurate information available.

# Codes

- 0 Dead
- 1 Alive

#### Instructions

- a. If no follow-up information is ever received, code the patient's vital status on the date of his/her last discharge from the hospital.
- b. If a patient has multiple primaries, all records should have the same patient vital status. Do not change a patient's vital status at discharge unless new follow-up information is available.
- c. There is no code for "unknown," since you must know at least whether the patient was alive or dead at the time he or she last left your facility.

# 72. CANCER STATUS (STATUS OF TUMOR)

Item Length: 1
Data Type: Numeric
ACoS: Required
State Registry: Required

# Description

This is a required 1-character field to record a code that indicates the presence or absence of clinical evidence of the patient's malignant of non-malignant tumor as of the *Date of Last Contact (or Death)*. Tumor status changes if the patient has a recurrence or relapse.

#### Codes

- 1 No evidence of this tumor
- 2 Evidence of this tumor
- 9 Unknown, indeterminate whether this tumor is present, not stated in the patient record

# Instructions

- a. Code the best available information concerning the tumor status of the patient as of the date of last contact or death.
- b. Code tumor status independently for each primary tumor. If a patient has multiple primaries, each record could have a different tumor status. If the patient has evidence of the other primary tumor, but does not have evidence of this tumor, code 1, no evidence of this tumor.
- c. Code patients who have hematopoietic disease (e.g., leukemia) that is in remission as no evidence of this tumor (code 1).
- d. Official death certificates do not always record the presence of tumors. If the registry abstract indicates that the patient had a malignant or non-malignant tumor immediately before death, code evidence of this tumor (code 2). Consult the registry physician advisor when questions arise. Decisions on tumor status coding can be based on information such as:
  - How much time elapsed between the last follow-up and patient's death?
  - Was the last follow-up and tumor status information from a medical source (physician, hospital admission)?
  - Are autopsy findings available to the registry?

Example: A prostate cancer patient has a two year history of metastatic disease. The patient had a bone scan at your facility in April 2003. The urologist's diagnosis was progressive bony metastases and the bone scan confirmed extensive bone destruction. The registrar finds an obituary documenting the patient's death in a nursing home in June 2003. Record the tumor status as "evidence of this tumor" (code 2).

# **FOLLOW-UP SOURCE**

Item Length: 1
Data Type: Numeric
ACoS: Required

State Registry: Required if available\*

\*Required if available for cases diagnosed 01/01/2008 and later.

# Description

This item records the source from which the latest follow-up information was obtained.

# Rationale

This data item is used by registries to identify the most recent follow-up source.

# Codes

Code	Label	Definition
0	Reported hospitalization	Hospital at another institution/hospital or first admission to the reporting facility.
1	Readmission	Hospitalization or outpatient visit at the reporting facility.
2	Physician	Information from a physician.
3	Patient	Direct contact with the patient.
4	Department of Motor Vehicles	The Department of Motor Vehicles confirmed the patient has a current license.
5	Medicare/Medicaid file	The Medicare or Medicaid office confirmed the patient is alive.
7	Death certificate	Information from the death certificate only.
8	Other	Friends, relatives, employers, other registries, or any sources not covered by other codes.
9	Unknown/ not stated in patient record.	The follow-up source is unknown or not stated in the patient record.

# **Description**

This is an optional 4-character field in the RMCDS abstract screen to record the *ICD-10* (*International Statistical Classification of Diseases and Related Health Problems*, Tenth Revision) code for the underlying cause of death. Record the cause of death listed on the death certificate. Central (state) registries are the primary users of this data item. Use the underlying cause of death (*ICD-10* code), even if believed to be in error. All underlying causes of death should be left-justified. The decimal point is assumed to be between the third and fourth digit, but should not be entered.

# **Special Codes**

0000 Patient alive at last follow-up

7777 State death certificate or listing not available

7797 State death certificate or listing available, but underlying cause of death not coded; or the coded underlying cause of death is not available

Note: When this field is left blank in the RMCDS program, the system defaults to "0000."

#### Instructions

- a. For all cases not meeting one of the above code descriptions and where the patient has died and the cause of death is known, record the *ICD-10* underlying cause of death code.
- b. Use code 7777 when the patient has died, but the death certificate is not available. Hospitals would almost always record code 7777 for cause of death.
- c. Use code 7797 when the patient has died, but the coded underlying cause of death is not available.
- d. The *ICD-10* codes consist of four characters a letter followed by two or three digits. If the fourth digit for the underlying cause of death is "blank," "X," or "-," use 9 for the fourth digit.
- e. Some codes have an optional fifth digit. The fifth digit is not used in coding cause of death.
- f. The *ICD-9-CM* code for cause of death obtained from the medical record should not be used for the underlying cause of death code if no death certificate is available. Use only the *ICD-10* code from the death certificate. If hospitals record cause of death from the medical record for their own use, the State Registry will replace it with the death certificate code.
- g. Examples:

Underlying Cause of Death	<u>ICD-10</u>	CODE
Cancer of the thyroid	C73	C739
Acute appendicitis with peritonitis	K35.0	K350
Adenocarcinoma of stomach	C16.9	C169

		Data Types Toyt
<b>73</b>	. REMARKS	Data Type: Text
		ACoS: N/A
		State Registry: Optional

# Description

This is an optional text field in the paper and RMCDS abstracts for recording information not elsewhere provided for or for overflow from other text fields. Facilities using other types of registry software should follow their vendor's instructions for recording text.

#### Rationale

Text is needed to justify the codes selected for the data items and to record information that is not coded at all. The text is used for quality control and special studies.

#### Instructions

The following kinds of information may be recorded in this field:

- a. History of symptoms
- b. Clinical findings
  - Example 1: Mass noted in right (rt.) breast 2 months ago; mammogram prior to admission (PTA) suspicious. Physical exam (PE) revealed 2 cm. mass in the upper outer quadrant (UOQ) of the right breast. No axillary lymphadenopathy noted.

Example 2: Pleural effusion or ascites, weight loss, etc.

- c. Diagnostic and metastatic work-up (type of procedures, dates, and results)
  - (1) Record only work-up related to the malignancy and the spread of the disease.
  - (2) When recording test results, include the interpretation (positive, negative, elevated, within normal limits) with the value because the definition or parameters for "normal" values may differ from one facility to another.
- d. Overflow from other text fields if additional space is needed.

#### PHYSICIAN IDENTIFICATION

FOLLOWING PHYSICIAN (FOLLOW-UP PHYSICIAN)
PRIMARY SURGEON
PHYSICIAN #3 (OTHER PHYSICIAN)
PHYSICIAN #4 (OTHER PHYSICIAN)

Item Length: 8

Data Type: Alphanumeric Left Justified, blank Fill ACoS: Required State Registry: Optional

# Description

This is an optional 8-character field in the RMCDS abstract screen for recording a unique number for each of the physicians participating in the management of the patient's care. Facilities that do not collect these items may leave the fields blank. The State Registry does not collect the items.

# Codes

Facilities are encouraged to use the physician's state medical license number for this field because this allows central registries to identify a physician who practices in multiple facilities by a single, unique number. Medical license numbers are maintained by the department (sometimes called the Medical Staff Office or Secretary) that performs medical staff credentialing in your facility.

Facilities may assign facility-specific numbers for the physicians. However, this is not ideal, since each physician will be identified by a different number in each hospital where he practices.

# **Definitions**

Following Physician The physician currently responsible for the patient's medical care. The following

physician is the first contact for obtaining information on a patient's status and subsequent treatment. Change this data item when follow-up becomes the

responsibility of another physician.

<u>Primary Surgeon</u> The physician who performed the most definitive surgical procedure. If the patient

did not have cancer-directed surgery, use the code for the surgeon who performed any surgery or did a surgical consultation. This information should not be changed

or updated even if the patient receives care from another surgeon.

Physician #3 Another physician involved in the care of the patient. ACoS recommends that this

data item identify the physician who performed the most definitive radiation therapy. If a primary radiation oncologist for the patient is designated in this field, the item should not be changed or updated even if the patient receives care from

another radiation oncologist.

Physician #4 Another physician involved in the care of the patient. ACoS recommends that this

data item identify the physician who gives the most definitive systemic therapy. If a primary medical oncologist for the patient is designated in this field, the item should not be changed or updated even if the patient receives care from another medical

oncologist.

# **Special Codes**

Following Physician

9999999 Following physician is unknown or an identification number is not assigned.

Primary Surgeon

blank The patient had no surgery (non cancer-directed or cancer-directed) and no surgical

consultation.

88888888 The physician who performed a surgical procedure was not a surgeon (e.g., radiation

oncologist, diagnostic radiologist, or general practitioner).

99999999 The primary surgeon is unknown or an identification number is not assigned.

# Physician #3

blank None; no additional physician.

9999999 Physician is unknown or an identification number is not assigned.

# Physician #4

Blank None; no additional physician.

9999999 Physician is unknown or an identification number is not assigned.

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# ADDITIONAL ITEMS IN THE RMCDS SCREENS

ACoS: See below State Registry: Optional

# Description

Fields for the optional items listed below are included in the RMCDS abstract screens for facilities that wish to collect them. Refer to the *FORDS* or the RMCDS manual, as indicated, for instructions in coding the items. Contact the State Registry if you wish to collect information in these fields and do not have copies of the *FORDS* codes.

Item	FORDS Page	ACoS Required Status
Comorbidities and Complications #'s 1-10	69-75D	Required
Date of First Surgical Procedure	131	Required
Date of Most Definitive Surgical Resection of Primary Site	133	Required
Date of Surgical Discharge	144	Required
Readmission to Same Hospital within 30 Days of Surgical Disc	harge 146	Required
Location of Radiation Treatment	150	Required
Radiation Treatment Volume	151	Required
Regional Dose: cGy	158	Required
Boost Treatment Modality	159	Required
Boost Dose: cGy	162	Required
Number of Treatments to This Volume	163	Required
Date Radiation Ended	166	Required
Reason for No Radiation	168	Required
Palliative Care	189	Required
Date of First Recurrence	195	Required
Type of First Recurrence	197	Required
Following Registry	202	Required
Next Follow-up Source	204	Required
Letter Frequency	-	N/A

**CENTRAL TUMOR REGISTRY NUMBER** (FOR STATE USE ONLY) Leave this item blank.

Item Length: 6 + 2 Data Type: Numeric

# **Description**

This is an 8-character field (when combined with sequence number). The Central Tumor Registry (CTR) Number is an internal number that will be assigned and used by the State Cancer Registry only. In the RMCDS program, it appears in the abstract screen and on reports as CTR # (Central Tumor Registry Number). There is a unique CTR number for each person in the central registry. If a person has more than one primary tumor, the sequence number will distinguish one tumor from the next.

In hospitals using the RMCDS program, the CTR number that appears in the hospital's abstract screen is the same as the hospital registry's accession number for the patient. The first four digits are the accession year (YYYY). The next five digits are the accession number (#####). The last two digits are the sequence number (SQ), so that the number looks like this: YYYY#####SQ.

When the hospital submits cases on diskette to the State Registry, the CTR number is automatically changed to the unique CTR number used by the central registry. Hospital accession numbers are also maintained in the central registry.

# DATE CASE REPORT RECEIVED (STAMP DATE)

(FOR STATE USE ONLY)

Item Length: 8
Data Type: Numeric

# Description

This is an 8-character field for the date the electronic or paper abstract (or source record) is received by the State Cancer Registry for the respective tumor. If multiple reports are received from two or more sources, the applicable date for each reporting source is maintained in the State record for the tumor. The item label is *Stamp Date* in the State RMCDS screens. RMCDS screens for hospitals do not include this item.

# Rationale

This item is used to assess and monitor the timeliness of reporting. Timeliness of abstracting (and reporting) is a concern for all standard-setting organizations and consequently, timeliness standards have been established. This item can be used with the *Date of First Contact* to measure timeliness of reporting by individual facilities to the State Registry.

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# **CHAPTER 6: CORRECTIONS AND FOLLOW-UP**

# **OVERVIEW**

This chapter describes how corrections, deletions, and follow-up information on previously submitted cases are reported to the State Cancer Registry. Part I explains the purpose for corrections and follow-up; who submits reports; and when, how, and where reports are submitted. Part II describes various methods to accomplish follow-up. Part III details how to complete the Correction and Follow-up Form, found at the end of this chapter. Part IV explains how to complete the Correction form for Multiple Patients, also found at the end of this chapter.

#### PART I: GENERAL INSTRUCTIONS

# A. Purpose

# 1. Corrections

The latest or most complete information and conclusions about a case should be reported. Over time, documentation may be added to a patient's medical record that was not available when an abstract was originally completed. Such information may, in the interest of accuracy, require modification of the originally reported data. For example, early diagnostic information may support a diagnosis of metastatic lung cancer. Later it may be learned that the original site of disease was breast cancer. In another case, more extensive work-up may reveal that disease originally thought to be malignant is benign and the case should be deleted from the State Cancer Registry database. For such cases it is important to correct the primary site, histology, and/or extent of disease as information becomes more complete. There is no time limit for making revisions that give better information about the **original** diagnosis or stage.

**Note:** This does not mean that as the disease progresses, the stage should be changed according to the latest stage of disease. Staging should reflect only information available through completion of surgery(ies) in the first course of treatment or within four months of diagnosis in the absence of disease progression, whichever is longer.

# 2. Follow-Up

Systematic, annual follow-up of cancer patients is an important function of the cancer registry. Annual follow-up achieves two important objectives:

- To encourage continued medical surveillance of patients for early detection and treatment of recurrences and subsequent cancer;
- To obtain information for patient care studies and survival.

Additional benefits of hospital-based follow-up efforts include provision of follow-up service to physicians and enhanced public relations resulting from the hospital's continued concern for patient welfare.

From an epidemiologic perspective, a statewide follow-up effort permits tracking of patients in the event that case control studies are required or patient contact is necessary to assess public health risks.

The American College of Surgeons, Commission on Cancer requires a successful follow-up rate of 90% for all cancer programs seeking approval.

# B. Who Submits Correction and Follow-Up Reports

Any hospital having correction or follow-up information about a patient who was previously reported to the State Cancer Registry may submit information on that patient to the State Cancer Registry.

# C. When to Submit Corrections and Follow-Up Information

# 1. Corrections

Corrections or modifications to previously submitted data should be completed and submitted to the State Cancer Registry as soon as possible after the need for correction is discovered.

#### Follow-Up

Follow-up should be performed at least annually for each patient, usually on the anniversary of the date of last contact.

Follow-up reports may be submitted to the State Registry at least quarterly, particularly for hospitals that treat a large number of cancer patients. Hospitals are encouraged to submit updated information more frequently in order to maintain a complete record of the patient's treatment and a current database for analytic purposes. This permits an orderly workflow at both the State Cancer Registry and the reporting hospital.

# D. How to Report Corrections and Follow-Up Information

Corrections, deletions, and follow-up can be submitted in a number of different ways that are outlined below.

# 1. Copies of the Original Paper Abstract

If your hospital reports by paper abstract, changes or follow-up may be submitted on a copy of the original paper abstract.

- a. Make a copy of the original form.
- b. In red, write "Correction," "Delete," or "Follow-Up" at the top of the form.
- c. In red, cross out the original data in the field to be corrected and write the corrected or follow-up information beside the old.

# 2. Correcton and Follow-Up Form

Changes and/or follow-up may be submitted on a "Correction and Follow-Up Form," explained in Part III of this chapter.

- a. Complete all identifying information on the form to ensure the appropriate case is corrected, deleted, or updated.
- b. Complete section D. "Corrections" or section F. "Follow-Up Information," as applicable.
- c. Make a legible copy of the original form and mail the copy to the State Cancer Registry, keeping the original at your hospital.

# 3. Corrections for Multiple Patients

Corrections for multiple patients, such as those identified on a discrepancy report from the State Cancer Registry, may be submitted by one of the following two methods:

- a. Write the correct information next to the error message on the discrepancy report and return the corrected report to the State Registry; or
- b. Record the corrections on the "Correction Form for Multiple Patients" explained in Part IV of this chapter.

# 4. Corrections by Telephone

Changes may be submitted by calling the State Cancer Registry at (317) 233-7158 with the correction or deletion. Changes of this type should be limited to five patients or less. Be prepared to identify the case by patient name, sequence number, and possibly date of birth or Social Security Number so that State Registry staff can change the correct record.

# 5. Computerized Registries

Follow-Up and Recurrence

When the State Registry processes disks received from hospitals with computerized registries, the most current follow-up information is automatically entered into the computer from the

diskettes. This includes date of last contact or death, patient's vital status, and cause of death, if applicable.

Other Changes (Corrections or Deletions)

All other information the hospital may have changed, updated, or corrected in any previously reported case is NOT automatically updated in the computer when the disks are processed. **These changes must be reported manually, in writing, or verbally.** 

The information will not be automatically updated in order to prevent writing over data which had been previously corrected or consolidated by State Registry staff. The system at the State Registry is designed so that when reports for a single case are received from multiple hospitals and there are significant differences in the information reported, they are not permitted to write over each other or merge until State Registry staff have analyzed and researched the differences and determined the best information and/or codes. The cases are then manually changed and consolidated. The work of the State Registry staff would be lost if new information from one of the hospitals could write over any changes made in the consolidation process. The consolidation process is described in more detail in Chapter 7 of this manual.

# E. Where to Send Correction and Follow-Up Reports

Envelopes should be carefully sealed and labeled "CONFIDENTIAL MEDICAL INFORMATION." The envelope should be clearly addressed:

Indiana State Cancer Registry Indiana State Department of Health 2 North Meridian Street, Section 7-D Indianapolis, IN 46204-3010

All reports submitted must be legible. Illegible forms will be returned to the hospital.

The hospital should keep a record of reports submitted to the State. Cancer Registry personnel will keep track of reports received from each hospital.

# F. Confidentiality

As correction and follow-up reports are being completed, care should be taken to ensure that the content of each is treated with the same level of security and confidentiality as the medical record. These reports are abbreviated medical records and should be treated as such. A full discussion of confidentiality is found in Chapter 8 of this manual.

#### PART II. FOLLOW-UP

Reporting annual follow-up data to the State Cancer Registry is optional. The State encourages hospitals to report follow-up information whenever possible in order to obtain a more complete record. Accurate and complete information about the current health of each patient may be difficult to obtain, but the importance of collecting this information is undeniable.

# A. Frequency of Follow-Up

Follow-up efforts should be initiated on those patients for whom no information has been received within the last 12 months. Cases are considered delinquent if no contact has been made within 15 months after the date of last contact. A follow-up (tickler) file must be maintained, either manually or by computer, by which to identify patients due for follow-up. For hospitals that submit follow-up information, it is recommended that follow-up data collection be a monthly task of the hospital that first treats a case.

# B. Cases to Include in Follow-Up

The American College of Surgeons, Commission on Cancer, requires annual follow-up on all analytic cases (Class of Case = 0, 1, 2, or 6).

A hospital may elect to report recurrence or follow-up information on any case that has been reported to the State Cancer Registry. See Chapter 3 on Reporting for further information on the reportable cases.

Patient of advanced age and stage of disease should not be assumed deceased and withdrawn from follow-up after a prescribed time period. These patients may have exceptional responses and occasionally be long-term survivors.

# C. Cases Not to Include in Follow-Up

- Carcinoma in situ of the cervix
- Non-analytic cases (class of case = 3, 4, 5, 8, or 9: cases neither diagnosed nor receiving any part
  of the <u>first</u> course of therapy at the reporting hospital)
- Patients residing in foreign countries
- Cases which were not required to be reported to the State Cancer Registry (see Chapter 3, Section D, pages 20-22)

# D. Data Fields to Include in Follow-Up

The State Cancer Registry needs minimal follow-up data on patients in its database in order to calculate survival time from date of cancer diagnosis to date of death. This data includes:

- Date of last contact or death
- Patient's vital status (alive or dead)
- Cancer status (with or without disease)

A full explanation of these items is found in Chapter 5 of this manual on pages 212-215.

There are additional data items relating to recurrences and follow-up that hospitals may want to collect for their registries: date and type of first recurrence, distant site(s) of first recurrence, subsequent treatment for persistent or recurrent disease, follow-up methods, quality of survival, and autopsy. Since the State Registry does not collect these items, they will not be explained here. Please refer to the *Registry Operations and Data Standards (ROADS)* for coding rules and information.

# E. Follow-Up Sources

- 1. Most follow-up information is obtained through review of hospital readmissions, outpatient visits, or letters to the patient's physician. Hospitals are encouraged to share follow-up information with other facilities that are following the same patient. Remember to re-contact physicians even though the first contact may not have been productive. After a period of time, the patient may have returned for a subsequent visit to the physician. When these methods are not effective in providing follow-up information, a variety of other sources may be employed.
- Hospital policy, consistent with legal requirements for confidentiality, should be developed governing potential contact with relatives, friends, etc. If hospital policy permits, patients may be contacted by letter or telephone. All patient contact should be accomplished in a responsible and compassionate manner. Many hospitals' policies caution against mention of the patient's diagnosis.
- 3. The Indiana Bureau of Motor Vehicles will provide a patient's address for a \$4.00 fee upon written request on letterhead stationery. The request must include the patient's name; date of birth; Social Security Number; last known address, if available, or at least the city; and driver's license number, if available. Mail the request to:

Bureau of Motor Vehicles Driver Services, Room N405 Indiana Government Center North Indianapolis, IN 46204

The date of renewal of the license may be used as a date of last contact if no further information can be obtained.

- 4. Voter Registration roles can be a source of addresses for patients who have moved. Date of the last election in which the patient voted or date of registration to vote may be used as the date of last contact if no further information can be obtained.
- 5. Miscellaneous methods of locating patients include the Social Security Administration office, medical and life insurance companies, local utility companies, and credit bureaus. Most of these sources will provide only last known address.
- 6. More information on follow-up techniques can be obtained through the American College of Surgeons, 55 East Erie Street, Chicago, IL 60611-2797. The "Cancer Registry Follow-Up Manual," May 1982, is also available free of charge (see Chapter 1, References, page 4).

# PART III: INSTRUCTIONS FOR COMPLETING CORRECTION AND FOLLOW-UP FORM

The number in front of the title of each item described below corresponds to the number on the Correction and Follow-Up Form for that data field. Shaded fields indicate items which are optionally reportable: completion is desirable, but not required. It is important to enter all information accurately and legibly.

#### A. Purpose of form

Check the box which describes your purpose for completing the Correction and Follow-Up Form.

#### 1. Correction

Check the "Correction" box if you are modifying or correcting a record you have previously submitted to the State Cancer Registry.

#### 2. Follow-Up

Check the "Follow-Up" box if you are reporting follow-up information.

#### 3. Delete Case

Check the "Delete Case" box if you want the State Cancer Registry to delete a record previously submitted. This might be used if, after reporting a case to the State Cancer Registry, you obtained additional information and concluded the case was non-reportable. Record the reason the case should be deleted in the "Remarks" section of the form.

# **B.** Patient Identification

The information in Items 4 through 6 should match the information previously submitted for the patient. It will be used to identify the record that requires the change or follow-up being reported.

#### Patient Name

Enter the patient's last name, first name, and middle initial according to instructions in Chapter 5, pages 41-47.

# 5. Social Security Number

Enter the patient's Social Security Number according to instructions in Chapter 5, page 72.

# 6. Date of Birth

Enter the patient's birth date according to instructions in Chapter 5, page 91.

# 7. State CTR #, if known

This is a unique 10-digit number assigned to every patient in the State Registry. Additional information on the CTR number can be found in Chapter 5, page 226.

If you have a report from the State Registry that lists the Central Tumor Registry (CTR) number, enter it in Item 7. The CTR number appears in the first column of Discrepancy Reports from the State Registry. After the 10-digit CTR number, a dash follows, and then the 2-digit sequence number, which should be recorded in Item 10 on the Correction and Follow-Up Form.

Leave the item blank if the CTR number is unknown or unavailable.

# C. Hospital and Tumor Identification

#### 8. Hospital Identification Number

Enter the 3-digit hospital ID number according to instructions in Chapter 5, page 37.

#### 9. Hospital Accession Number

Enter the 9-digit hospital Accession Number according to instructions in Chapter 5, page 49.

# 10. Sequence Number

Enter the 2-digit Sequence Number according to instructions in Chapter 5, page 52.

# 11. Original Primary Site

Enter the *ICD-O-3* primary site code number as originally submitted to the State Registry according to instructions in Chapter 5, page 103. If primary site is the item you want to correct or change, the corrected code will be reflected in Item 12 where corrections are described.

#### D. Corrections

#### 12. Item Number

This item applies only if you initially reported the case on a paper abstract. Enter the item number of the field you are correcting that corresponds to the item number on the original Hospital Abstract. For example, if you are correcting Summary Stage, which is Item 40 on the Hospital Abstract form, enter "40" on the correction form.

#### Field Name

Enter the name of the item (field) you want to correct or change. For example, if you are changing the primary site code, enter "Primary Site."

# 14. Change From

Enter the information that was originally submitted for the field you are correcting. If you are changing the Summary Stage from "localized" to "in situ," for example, enter the <u>code</u> you originally submitted (1). Enter the code first, and the description if space allows. For example, enter 1 – localized.

#### 15. Change To

Enter the new information for the field you are correcting. If you are changing the Summary Stage from "localized" to "in situ," for example, enter the <u>code</u> you want to change the Summary Stage to (0). Enter the code first, and the description if space allows. For example, enter 0 – in situ.

#### E. Remarks

The "Remarks" field is to be used to record any information that may be helpful to you or State Cancer Registry staff who will be entering the data. The type of information that might be recorded here includes an explanation of the correction if it is anything other than routine. If a case is being deleted, record the reason in this field.

# F. Follow-Up Information

The "Follow-Up Information" fields allow for submission of up to three years of follow-up information. The hospital should keep the original abstract and send a copy to the State Registry. Additional years of follow-up can then be added to the original Correction and Follow-Up form, with a copy being sent to the State every year.

After each 12-month follow-up contact is made, complete the next follow-up information section.

# 16. Date of Last Contact

Enter the date of the most recent patient contact or the patient's date of death. Complete this section according to instructions in Chapter 5, page 212.

#### 17. Vital Status (Patient Status)

Enter the patient's vital status (alive or dead) as of the last date of contact. Complete this section according to instructions in Chapter 5, page 214.

# 18. Cancer Status

Enter the patient's cancer status (with or without evidence of cancer) for this primary as of the last date of contact or death using the best available information. Complete this section according to instructions in Chapter 5, page 215.

#### 19. Cause of Death

Enter the ICD-10 underlying cause of death code listed on the death certificate. Complete this section according to instructions in Chapter 5, page 220.

# **Special Codes**

- 0000 Patient alive at last follow-up
- 7777 State death certificate or listing is not available
- 7797 State death certificate or listing is available, but the underlying cause of death is not coded or the coded underlying cause of death is not available

# 20. Submitted By

Enter the name or initials of the person completing the Correction and Follow-Up Form. The name or initials may be legible printed, written, or typed. The signature of the preparer is not required. This information is collected in case the State needs to contact the preparer for questions.

# 21. Date Completed

Enter the date the form was completed. The date may be legibly printed, written, or typed.

#### PART IV: INSTRUCTIONS FOR COMPLETING CORRECTION FORM FOR MULTIPLE PATIENTS

The "Correction Form for Multiple Patients" can be used to report corrections for up to four different patients. The form can be used to address questions identified on the State Registry's discrepancy lists or to report any corrections on multiple patients.

#### A. Hospital Identification

- 1. Enter the name of your hospital. If there is more than one hospital with the same name (e.g., there are six St. Joseph hospitals in Indiana), add the city name or an abbreviation of the city.
- 2. Enter the 3-digit hospital identification number according to instructions in Chapter 5, page 37.

#### **B.** Corrections

- 1. Enter the patient's last and first names in the space under the item title Name according to instructions in Chapter 5, pages 42-47.
- 2. Enter the Central Tumor Registry (CTR) number, if known, as it appears in the first column of the Discrepancy Report. The first 10 digits are the CTR number, followed by a dash, and then the 2-digit Sequence Number (e.g., 0000123456-00). Additional information on the CTR and Sequence Numbers can be found in Chapter 5, pages 226 and 52.
- 3. Enter your hospital's Accession Number, according to instructions in Chapter 5, page 48. The first 4 digits are the year the patient was first accessioned, followed by a dash, and then the five digit Accession Number.
- 4. On lines 1-5, record an explanation of the change(s) being reported. The change(s) should be recorded as described for the "Correction and Follow-Up Form" on page 236. If the correction involves a change of codes, record both the old and the new codes.

# C. Submitted By and Date

Enter the name or initials of the person completing the form on this line. The name or initials may be legibly printed, written, or typed. The signature of the preparer is not required. This information is collected in case State Registry staff need to contact the preparer for questions.

Enter the date the form was completed. The date may be legibly printed, written, or typed.

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# **CHAPTER 7: QUALITY CONTROL**

#### A. OVERVIEW

Quality control is the cancer registry function concerned with the assessment and improvement of data quality. The components of quality include completeness, accuracy, and timeliness.

#### Goals

- To detect and correct errors or omissions in existing data;
- To identify and effectively address opportunities for improvement in training, documentation, and/or systems in order to assure the quality of subsequent data collection.

# **Components of Quality Control**

The State Registry quality control activities include the following:

- Analysis of observed/expected completeness rates
- Casefinding audits
- Reabstracting and re-coding audits
- Visual editing of data quality
- Computer editing of data quality
- Evaluation and consolidation of case-sharing and duplicates
- Procedure manual (documentation) maintenance
- Staff training and development
- Feedback and consultation from quality control activities to data collectors
- Resolution of discrepancies

# B. ASSESSMENT/IMPROVEMENT OF DATA ACCURACY AND COMPLETENESS

#### 1. Observed/Expected Completeness Rates

#### Case Volume

Case volume will be monitored to assess and improve the completeness of data. The actual number of cases reported by each facility will be compared to an estimated expected volume. The expected case volume for a year is based on an assessment of the number of cases reported in each of the preceding five years. An annual caseload can be estimated by the number of acute care medical and surgical beds at the facility. A hospital with 250 acute medical and surgical beds may typically see 250 new cancer cases per year. For small hospitals without radiation therapy centers, this figure is probably within 20% of the actual caseload for the first years of the registry. For hospitals offering radiation therapy, 50% is added to the total number of beds to determine annual caseload (e.g., a hospital with 100 beds would see 150 cancer cases per year). This formula is not reliable for major referral centers.

Should fewer reports be received during a given time frame than expected, the reporting source will be contacted. The Indiana State Cancer Registry personnel will be available for consultation and assistance. A review would include an examination of the hospital's patient index file; pathology reports; chemotherapy, radiation therapy, and outpatient log books; diagnostic or disease index; and print-outs of cancer-related diagnostic codes from the billing system.

#### **Patterns**

Indiana data will be compared with national averages in order to assess and improve the completeness of data. Based on data from the *Surveillance, Epidemiology, and End Results (SEER)* Program of the National Cancer Institute, the proportion of cases from each of the common organ sites will be compared to Indiana data. For example, SEER estimates that in 1997, lung cancer accounts for approximately 13% of all new cases; breast cancer accounts for 30% of all new cases in women; and prostatic cancer accounts for 43% of new diagnoses in men. These types of statistics

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will be used to determine whether Indiana data are comparable to national data. Any discrepancies will be investigated.

# 2. Casefinding Audits

Casefinding audits will be performed to assess and improve the completeness of reporting. The audit is a study to verify that a facility is reporting all applicable newly diagnosed cancer cases and to help the facility improve casefinding procedures if needed. The audit involves reviewing the facility's casefinding procedures and all sources for potential cases in the facility. The cases identified in this review are compared with cases reported and missed cases are documented. The reviewer calculates a completeness rate from these numbers and compares the rate with the completeness rate goal of 95%.

Each year the State Registry will select up to 20% of Indiana hospitals for casefinding audits. Sample specifications will be based on hospital annual caseload. Six months will be reviewed for hospitals with 0-100 annual cases. Three months will be reviewed for hospitals with 101-499 annual cases. One month will be reviewed for hospitals with 500 or more annual cases.

The State Registry will make consultative recommendations to the hospital registrar during the audit and will submit a written report of results and recommendations to the hospital and the State Registry within thirty days of the audit.

# 3. Reabstracting Audits

Reabstracting audits will be performed to assess and improve data accuracy in terms of the data collectors' adherence to established principles of coding, abstracting, and staging. The audit involves reviewing the facility's source records for randomly selected cases and reabstracting selected data elements. The reabstracted items are compared with the facility's abstract and discrepancies are reviewed to identify needs for clarification, corrections, and education.

Each year the State Registry will select up to twelve (10%) Indiana hospitals for reabstracting audits. The sample will be limited to a subset of cases diagnosed the previous year in the same half of the year as the time of the audit.

The State Registry staff will make consultative recommendations to the hospital registrar at the time of the audit and will submit a written report of results and recommendations to the hospital and the State Registry within thirty days of the audit.

# 4. Recoding Audits

Recoding audits may be performed to assess and improve the accuracy of data from new coders or from coders with educational needs identified by other quality control activities. The audits involve independently reassigning codes to abstracted text information or from copies of specific medical record documentation requested from the facility. The recoded items are compared with the original codes submitted and discrepancies are analyzed to identify needs for clarification, correction, and education.

The State Registry staff will submit a written report of results and recommendations to the hospital and the State Registry within thirty days of the audit.

#### 5. Visual Edits

Visual editing will be performed to assess and improve data accuracy and completeness. Visual reviews will be performed on abstracts received by State Cancer Registry staff to determine if data are logical and internally consistent. Dates of birth, accession years, admission and discharge, initial diagnosis, and treatment will be monitored for logical progression. Accession number, sequence number, and class of case will be visually reviewed for logic. Agreement with laterality, site codes, histology, and sex will be reviewed for logical consistency, both manually and through computerized edits. Completeness will be assessed by monitoring the number of "unknowns" or blanks in demographic and cancer data.

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Transcription accuracy reflects the quality of procedures for transferring the data from the paper abstract to electronic medium. Before the data are entered by State Cancer Registry personnel, each screen will be carefully checked against the abstract for transcription errors prior to transmission. Hospitals reporting data electronically should perform transcription quality control prior to submission.

Quality control reviews will be performed on reports before the data are released. In addition to the routine computerized edit checks, the subset of cases used in the report will be checked for duplicate cases to ensure patients are not counted more than once for each tumor. Patterns in the data will be studied for inconsistencies. For example, a listing of pediatric cases containing colon, breast, or prostate cancers would identify a need for further review and action. Other examples include comparing ZIP Codes to matching county codes, or ensuring all leukemia cases have a primary site code of C42.1.

#### 6. Computer Edits

The accuracy of all data received by the State Cancer Registry will be assessed by applying standard computerized data edits. The computerized edits include the following: single field (to check for valid codes), multi-field (to check for consistency and logic between different fields), multi-record (to check for consistency between multiple sequences), and multi-database (to check for consistency between different hospitals seeing the same patient for the same tumor). Inconsistencies or discrepancies not detected during manual edit checks will be identified by these edits. Invalid codes will be identified in this process. The reporting source will be contacted as needed for correction, clarification, or completion of required data elements.

The State Registry will apply the Rocky Mountain Cancer Data Systems' (RMCDS) edit program to produce a list of cases with potential problems. Three types of discrepancies are identified on the list. An (E) indicates an Error of a general type, an invalid or missing code, etc. A (W) indicates a Warning, which is a possible error that should be evaluated. An (I) is an Inconsistency between two fields. The list will be sent to the hospital where each discrepancy should be reviewed promptly. If you would like a copy of the edit checks from the Rocky Mountain Cancer Data Systems procedure manual, contact the State Registry.

When facility staff disagree with the Error, Warning, or Inconsistency (because the original information is, after review, found to be correct), they should make a note on the error list by writing "correct" or "override" next to the error, warning, or inconsistency message. Medical record documentation (pathology reports, etc.) to support the decision should be attached. The Registry staff will "override" the edit if possible, or ask the hospital for further clarification.

# **RMCDS** Registries

Facilities using the RMCDS program should apply the RMCDS edits to all records and correct all errors before submitting data to the State Registry. If the State sends a list of additional discrepancies found in the database (from old data that was previously entered from paper abstracts), the facility should correct, if necessary, any errors <u>both</u> in their computer <u>and</u> on the list of errors, which must be returned to the State.

# Other Computerized Registries

Facilities that receive a list of records that did not pass edits, should check and make any necessary corrections on the case in their database. They must <u>also</u> write the correction on the discrepancy list and return the list to the State Registry where the error will be manually corrected in the State's database. CORRECTING THE ERROR IN THE HOSPITAL DATABASE WILL NOT CORRECT THE ERROR AT THE STATE REGISTRY. The State Registry must manually correct errors instead of copying corrected records from the hospital's diskette in order to prevent writing over data that had previously been corrected or consolidated by State Registry staff. After correction, the edits are applied to the record again to make sure the correction does not cause another type of error.

# Paper Registries

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Facilities that receive a list of records that did not pass edits should check and make any necessary corrections on their copy of the paper abstract. They must <u>also</u> write the correction on the error list and return the list to the State Registry where the error will be manually corrected in the State's database.

#### 7. Consolidation

The State Cancer Registry will create a unified record for each case that is reported by multiple sources. Duplicate reports for a single case may be received from the same hospital, multiple hospitals, death records, or another state registry. In order to accurately determine the incidence of cancer in Indiana, duplicate reports for a single case will be identified and any discrepancies between reports will be resolved. The reports will then be consolidated into a single record.

The consolidation process is performed in one of two different ways, depending on which data elements are different. If critical, identifying data elements are identical (e.g., patient name, date of birth, sex, sequence number, primary site code, etc.), the case coming in on diskette merges with the duplicate case already in the database. Some of the decision making process is done automatically by the computer (e.g., a known code will generally take precedence over an unknown code 9). After the disk is loaded, the registry prints a "Difference Report," which lists any differences between what was in the original State database with what came in from the hospital disks. The Registry staff review these Difference Reports and make any needed changes. All changes made in the consolidation process will be reported to the applicable data collector for correction and feedback.

If identifying data elements are not identical, the second case coming in to the State Registry will be added as a separate new case (tumor). These cases will be identified for review by printing special reports of possible duplicates. State Registry staff will manually review, research, and merge the cases as appropriate. Using all available information, the State Registry determines the best and most accurate codes. This process will involve contact with the reporting sources when necessary. All changes made in the consolidation process will be reported to the applicable data collector for correction and feedback.

The Class of Case (who diagnosed the tumor vs. who treated it) is important when deciding which codes may be the most accurate. For example, a small hospital may diagnose a patient through a biopsy and send the patient to a larger facility for definitive treatment. The larger hospital may list the diagnosis date as the date the tumor was removed and pathologically examined. However, the date of the initial biopsy from the smaller diagnosing hospital is the date of diagnosis State Registry staff would use when consolidating the information from the two hospitals. Conversely, the larger hospital's primary site and staging codes will generally be more accurate, since they have more information about the extent of disease from the operative and pathology reports.

When reports from different facilities are merged into a unified record at the State Registry, the record retains the identification of up to four of the reporting facilities along with the data items which are specific to the institution (accession number, sequence, admission and discharge dates, medical record number, and class of case). Treatment and procedure codes are retained as space permits. The rest of the demographic information for the patient, such as address at diagnosis, ZIP Code, Social Security Number, birth date, sex, race, etc., should be the same among hospitals, regardless of where the patient was seen.

When the State Registry changes the data a hospital has reported, it does not necessarily mean the data are wrong. The hospital reported the correct information available at that time, but subsequent data may be more specific or accurate and require a change in some of the original information. It is acceptable to change the primary site, histology, and extent of disease as information becomes more complete.

#### 8. Procedure Manual Maintenance

Current, written documentation of the State Registry's definitions and methods will be maintained in this policy and procedure manual, which is provided to all State Registry employees, contract

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consultants, and employees of reporting facilities. The manual documents the Registry's data set definitions, codes, coding rule interpretations, and procedures. The standards of ACoS, NAACCR, and SEER are incorporated in the manual to the extent possible. Appropriate portions of the documentation will be provided to investigators and users of the data, as needed, to explain definitions and methods.

A Policy and Procedure Manual maintenance system will be utilized for updating the documentation and keeping it current. A library of revisions to the manual will be kept at the State Cancer Registry. When revised, dated pages will be provided to all Registry staff, contract consultants, and reporting facilities. The State Cancer Registry will also maintain an "unusual case" reference file to aid in consistent data collection for difficult cancers.

Information from other quality control activities will be used in assessing the need to revise the procedure manual.

## 9. Staff Training and Development

The State Cancer Registry will provide training opportunities for employees of the State Registry and employees of reporting facilities. Training programs will be developed in cooperation with the Indiana Cancer Registrars Association, Indiana Health Information Management Association, and Rocky Mountain Cancer Data Systems. Training will provide feedback to State Cancer Registry staff on the quality and effectiveness of services provided to reporting sources and the public.

Training programs will be based on standard reference manuals and may address the following areas:

Anatomy and physiology
Medical terminology
Site specific or other topics in oncology
Reporting requirements
Confidentiality and information security
Casefinding
Abstracting/coding/staging
Follow-up
Quality control
Data processing (computer software)
American College of Surgeons updates
Hospital based cancer/tumor registry management
Topics identified through other quality control activities

#### 10. Feedback and Consultation

The results of quality control activities will be reported to the applicable data collector to maintain data quality and eliminate recurring errors. Feedback may be written or by telephone call or one-on-one meetings. Feedback to the reporting facilities will include the following:

- Information about changes or corrections made to abstracts at the State Registry
- Discrepancy lists resulting from computer or visual edits
- Results of casefinding and reabstracting audits with analysis of discrepancies and recommendations for improvement
- Information from analysis of observed/expected completeness rates.

The abstractor's identification and date completed are required items in the RMCDS and paper abstracts and are useful in identifying contacts for feedback. A complete list of the abstractors and/or contact person for each hospital will be maintained at the State Cancer Registry. When feedback is indicated, the questions will be directed to the person on this list.

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#### C. ISSUES RELATED TO QUALITY

#### 1. Timeliness of Data

Data collection must be conducted according to schedule. With the exception of early deaths, no case should be abstracted less than four months after admission. Abstracting too soon may result in the omission of important information from the database if complete information is unavailable at the time of abstracting. Cases are due at the State Registry no later than six months following a confirmed diagnosis. Abstracting too late reduces the usefulness of the cancer registry data and reports. Cases submitted by each reporting source will be monitored for timely receipt.

#### 2. Personnel

Data collection in reporting facilities must be performed by knowledgeable and qualified individuals. The individuals serve as the primary abstractors and may be responsible for staff supervision, cancer case auditing, and report writing.

The Commission on Cancer, American College of Surgeons encourages registry staff to maintain Certified Tumor Registrar (CTR) credentials. The State Cancer Registry can provide hospitals with information on how to become a CTR, certified by the National Cancer Registrars Association (NCRA). Information on NCRA is found on page 8 in Chapter 1 on References.

#### 3. Use of References and Edits

Hospital staff should use available reference materials, many of which are free, rather than trying to memorize codes. Hospitals with computerized registries should ensure all records pass computer edits at the hospital level before sending data to the State. Standard edits, such as the EDITS project system developed by NAACCR, are available from standard setting organizations.

# 4. Maintenance of Logs and Records

Hospitals must keep documentation by date sent of reports submitted to the State Cancer Registry. Hospitals submitting paper abstracts must submit a legible copy of the original to the State Cancer Registry and keep the original for their records. State Cancer Registry personnel will keep a copy of discrepancy reports returned to the reporting source for completion, clarification, and correction.

#### 5. Submitting Correction or Follow-Up

Chapter 6 details how to submit corrections and follow-up information. Two correction forms, which permit changes or deletions to be made to the Hospital Abstract Form, are explained. The Correction and Follow-Up Form also allows reporting of annual follow-up information.

# 6. Other Resources

Further information on quality control procedures may be obtained by requesting <u>Volume I</u>: <u>Cancer Program Standards</u> published by the Commission on Cancer, American College of Surgeons. Another excellent resource is "Quality Control for Cancer Registries," available from the National Institutes of Health, Statistical Analysis and Quality Control Center (see resources in Chapter 1). The State Cancer Registry also complies the NAACCR <u>Standards for Cancer Registries</u>, <u>Volume III</u>: <u>Standards for Completeness</u>, <u>Quality</u>, <u>Analysis</u>, <u>and Management of Data</u>.

# **CHAPTER 8: CONFIDENTIALITY**

#### A. OVERVIEW

# 1. Purpose

The State Cancer Registry is committed to preserving the confidentiality of information obtained for medical, educational, research, and statistical purposes. Confidentiality policies and procedures are maintained in all phases of the State Registry operations in order to:

- Protect the privacy of individual patients;
- Protect the privacy of the facilities reporting the cases;
- Abide by applicable confidentiality-protecting legislation or administrative rules.

#### 2. Definition

Confidential data includes any information that identifies a specific patient, health care professional, or institution. The obligation to protect confidentiality extends indefinitely, even after the death of the patient.

Legal requirements for confidentiality are described in IC 16-38-2-(4-7) and 410 IAC 21-1-5, found in Appendix A.

#### **B. RESPONSIBILITY**

# 1. Reporting Source (Hospital or Other Health Care Provider)

The reporting source (hospital or other health care provider) is responsible for protecting the confidentiality of registry data collected and maintained on site and for submitting data to the State Registry in a way that protects confidentiality. The hospital should develop and implement confidentiality policies and procedures that address staff training, access control, record/abstract handling and storage, and release of registry data.

Paper abstracts must be handled and stored in a way that prevents unauthorized individuals from viewing confidential data. Information maintained in computerized systems must be protected by physical and electronic measures to control access to confidential data. Hospitals should mail copies of completed abstracts, tapes, or diskettes promptly to the State Registry, following the instructions in Chapter 3 of this manual for sealing and labeling the container and for keeping records of the cases submitted.

# 2. State Registry

The Program Director is ultimately responsible for information security at the State Registry. This responsibility includes ensuring that State Registry staff are accountable for compliance with the confidentiality policies and procedures of this chapter.

#### C. STATE REGISTRY POLICIES AND PROCEDURES

### 1. Staff Awareness

- a. All State Registry personnel and consultants receive specific training about the confidentiality of registry information and their responsibilities.
- b. All personnel handling or having access to cancer registry data are required to sign a Confidentiality Agreement. This includes staff from other departments, sections, or programs that are outside the State Cancer Registry but within the Indiana State Department of Health. The agreement documents that the employee has read and understands the State Cancer Registry policies for handling the data, agrees to abide by the policies, and is aware that failure to comply with any of these requirements constitutes a class A misdemeanor which

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will result in disciplinary action in accordance with State policies. The agreement remains in effect after cessation of employment. A copy of the Confidentiality Agreement is available from the State Cancer Registry upon request.

#### 2. Access Control

- a. A current, written list of persons with legitimate access to confidential cancer data is kept in the State Cancer Registry office. The nature and extent of their access to registry data are defined and are restricted to the information needed to do his/her job.
- b. All office doors are locked except when occupied by authorized State Cancer Registry staff.
- c. Employees are provided with the equipment for ensuring the physical security of confidential information. Confidential patient abstracts are stored in locked file cabinets. Backup tapes of the statewide database are stored in a locked, fireproof safe.
- d. Field staff maintain abstracts, diskettes, and/or printed reports in locked briefcases which are kept in a secure place when unattended. Access to confidential information is limited to authorized hospital personnel. Discussions regarding patient records occur only in settings where privacy is assured.
- e. The computer system provides access only to authorized individuals. The system has a three tiered level of security.
  - 1) The first level is the user Login Name. Each central registry staff logging into the network file server must enter his/her unique user login name.
  - 2) The second level is the confidential password, established by the user. The password is altered on a regular basis and when there is concern that security may be in jeopardy.
  - 3) The third level is the password to gain entry to the Rocky Mountain Cancer Data Systems (RMCDS) software. Network users who need the data for epidemiologic studies may be allowed limited access to only the non-confidential portions of the database. The RMCDS program is set up to allow "Read Only" for such individuals.
    - When a user is no longer employed at the State Registry, his/her password and access codes are deactivated immediately.
- f. Disclosure or sharing of codes, numbers, or names used to access the computer is strictly prohibited.
- g. When printed reports containing confidential information are no longer needed, they are disposed of by shredding.

# 3. Data Collection and Management

# a. Abstract Forms

Mail labeled "CONFIDENTIAL MEDICAL INFORMATION" is opened only by designated State Registry staff. Such mail is kept in a secure location before and after it is processed. State Cancer Registry personnel stamp each form with the date received and maintain a register by hospital documenting the date the batch was received, the date the batch was entered, the number of forms enclosed, and the accession year for the cases. The State Registry retains the abstract forms and registers indefinitely. After processing, abstract forms are filed by hospital, accession year, and accession number.

# b. Electronically Submitted Data

The State Cancer Registry handles diskettes containing confidential data with the same level of security and confidentiality as paper abstracts. The diskettes are kept in a secure location

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before and after they are processed. State Registry personnel maintain a register documenting the date the diskettes were received, the hospital name and number, the number and size of disks, the applicable software vendor, disk label information, and the input file name.

After the diskettes are loaded and converted into the statewide database, they are filed in a secure area.

# c. Quality Control Communications

When State Registry quality control (QC) activities require returning abstracts, inquiry forms, or discrepancy lists to reporting facilities, the mailings are carefully sealed and labeled "CONFIDENTIAL MEDICAL INFORMATION." When telephone calls are made to address QC issues, reasonable efforts are made to ensure the conversations are private and addressed to an authorized data collector at the reporting facility. When QC communications are transmitted by electronic mail (e-mail), patient identifying information will be limited to accession numbers. Patient identifying e-mail received at the State Registry is treated with the same level of security and confidentiality as other confidential medical information.

#### d. Facsimile Transmission

Confidential information should be transmitted via facsimile <u>only</u> when urgently needed for patient care. When such transmission is necessary, the cover page will include a confidentiality notice that indicates the information is confidential and limits its use. After transmission, a follow-up call will be made to verify that the information was sent to the appropriate destination.

# 4. Disaster Recovery

The registry information system is backed up regularly and back-up tapes are stored in a locked, fireproof safe. Back-up tapes are sent to RMCDS at least twice a year for off-site storage.

# 5. Sabotage

Anti-virus software is used to help detect and block computer viruses and other forms of sabotage.

# 6. Release of Registry Data

# a. Hospital Requests

Confidential information may be released by authorized State Registry personnel to health care providers and institutions upon verbal or written request and without further review procedures under either of the following circumstances:

- 1. The requestor is directly involved in the care or follow-up of the patient;
- 2) The information requested is from the hospital's own registry.

# b. Patient or Individual Requests

The State Cancer Registry staff do not respond to individuals requesting whether or not the State Registry contains information about them. Individuals making such requests are referred to their treating physician.

#### c. Physician Requests

Confidential information may be released to physicians and local health officers for diagnostic and treatment purposes if the patient signs a written consent and the patient's attending physician gives verbal or written consent to the release.

# d. Other States

Pursuant to IC 16-38-2-7, effective May 15, 1988, the Indiana Cancer Registry may release confidential information concerning individual cancer patients to the cancer registry of another state under the following condition: The other state has entered into a reciprocal agreement

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with the State Cancer Registry which provides that information that identifies a patient will not be released to any other person without the written consent of the patient.

#### e. Other External Requests

- 1) Requests for use of confidential data are handled in accordance with IC 16-38-2-(5-7).
- 2) Confidential cancer registry data will <u>not</u> be made available for the following purposes:
  - a) Businesses that are trying to market a product to cancer patients;
  - b) Health care institutions that are trying to recruit new patients;
  - c) Insurance companies that are trying to determine the medical status of a patient.
- 3) Requests for State Cancer Registry data for other purposes, such as research projects, are processed as outlined below.
  - a) The request must be submitted in writing and include the following information:
    - The purpose for which data are needed or an outline of the proposed research with a justification of the need for the data;
    - The information required;
    - The names of the persons who will have access to the confidential information;
    - The time period for which the data are needed.

A record is kept of the date and type of all requests.

- b) The written request is submitted to the Indiana State Department of Health Data Request Committee for review. The committee must approve the request before release can be made. The State Cancer Registry reserves the right to limit the amount of data to be provided to an individual requestor.
- c) If the request is approved, researchers must sign an agreement acknowledging responsibility to maintain patient confidentiality, cite the source of the data in any publication or presentation, and provide the State Cancer Registry with copies of any publications or presentations that may use the data prior to their release. Violation of any part of this agreement shall prevent further access to the data, and shall result in a letter of reprimand to the chief executive officer of the researcher's institution. In addition, other researchers at the institution may be denied access to the data until the Program Director is assured that no other violations will occur.

All requestors must assure:

- That he/she is bound by the principles of confidentiality observed by the personnel of the State Cancer Registry;
- That the data will not be used for purposes other than those agreed upon at the time of release:
- That the data will not be released to unauthorized individuals or parties; and
- That data that are no longer needed for the designated purpose will be returned or destroyed.

# f. State Initiated Requests

The Program Director monitors all state initiated research activities to ensure that only relevant activities are undertaken. State affiliated researchers are expected to abide by the same restrictions as outside researchers.

# APPENDIX A: LEGISLATION AND REGULATIONS

INDIANA CODE 16-38-2 Public Law 2-1993, Section 21

# IC 16-38-2-1 Cancer registry; establishment

- Sec. 1. (a) The state department shall establish a cancer registry for the purpose of:
  - (1) recording:
    - (A) all cases of malignant disease; and
    - (B) other tumors and precancerous diseases required to be reported by:
      - (i) federal law or federal regulation; or
      - (ii) the National Program of Cancer Registries;

that are diagnosed or treated in Indiana; and

- (2) compiling necessary and appropriate information concerning those cases, as determined by the state department; in order to conduct epidemiologic surveys of cancer and to apply appropriate preventive and control measures.
- (b) The department may contract for the collection and analysis of, and the research related to, the epidemiologic data compiled under this chapter.

As added by P.L. 2-1993, SEC.21. Amended by P.L. 93-2001, SEC.1; P.L. 17-2004, SEC.2.

# IC 16-38-2-2 Development of registry from existing data

Sec. 2. The state department shall, to the greatest extent possible, utilize information compiled by public or private cancer registries in the development of a statewide cancer registry under this chapter.

As added by P.L. 2-1993, SEC.21.

#### IC 16-38-2-3 Reports

- Sec. 3. (a) The following persons shall report to the cancer registry each confirmed case of cancer and other tumors and precancerous diseases required to be recorded under section 1 of this chapter:
  - (1) Physicians.
  - (2) Dentists.
  - (3) Hospitals.
  - (4) Medical laboratories.
  - (5) Ambulatory outpatient surgical centers.
  - (6) Health facilities.
  - (b) A person required to report information to the state cancer registry under this section may utilize, when available:
    - (1) information submitted to any other public or private cancer registry; or
    - (2) information required to be filed with federal, state, or local agencies; when completing reports required by this chapter. However, the state department may require additional, definitive information.

As added by P.L. 2-1993, SEC.21. Amended by P.L. 17-2004, SEC.3.

### IC 16-38-2-4 Confidentiality

Sec. 4. Except as provided in sections 5, 6, and 7 of this chapter, information obtained under this chapter by the state department concerning individual cancer patients is for the confidential use of the state department only.

As added by P.L. 2-1993, SEC.21.

# IC 16-38-2-5 Access to confidential information for research purposes

- Sec. 5. The state department shall grant any person involved in a legitimate research activity access to confidential information concerning individual cancer patients obtained by the state department under this chapter if all of the following conditions are met:
  - (1) The person conducting the research provides written information about the following:
    - (A) The purpose of the research project.
    - (B) The nature of the data to be collected and how the researcher intends to analyze the data.
    - (C) The records the researcher desires to review.
    - (D) The safeguards the researcher will take to protect the identity of the patients whose records the researcher will be reviewing.
  - (2) The proposed safeguards are adequate to protect the identity of each patient whose records will be reviewed.
  - (3) An agreement is executed between the state department and the researcher that meets all of the following conditions:
    - (A) Specifies the terms of the researcher's use of the records.
    - (B) Prohibits the publication or release of the names of individual cancer patients or any facts tending to lead to the identification of individual cancer patients.

As added by P.L. 2-1993, SEC.21.

# IC 16-38-2-6 Additional information requests; individual patients; consents

Sec. 6. Researchers may, with the approval of the state department, use the names of individual cancer patients when requesting additional information for research purposes or soliciting an individual patient's participation in a research project. However, if a researcher requests additional information for an individual cancer patient's participation in a research project, the researcher must first obtain the oral or written consent of the patient's attending physician. If the consent of the patient's attending physician is obtained, the researcher must then obtain the individual cancer patient's written consent by having the patient complete a release of confidential medical information form.

As added by P.L. 2-1993, SEC.21.

#### IC 16-38-2-7 Release of confidential information

- Sec. 7 The state department may release confidential information concerning individual cancer patients to the following:
  - (1) The cancer registry of another state if the following conditions are met:
    - (A) The other state has entered into a reciprocal agreement with the state department.
    - (B) The agreement provides that information that identifies a patient will not be released to any other person without the written consent of the patient.
  - (2) Physicians and local health officers for diagnostic and treatment purposes if the following conditions are met:
    - (A) The patient's attending physician gives oral or written consent to the release of the information.
    - (B) The patient gives written consent by completing a release of confidential information form.

As added by P.L. 2-1993, SEC.21.

#### IC 16-38-2-8 Immunity from liability

Sec. 8. A person who reports information to the cancer registry system under this chapter is immune from any civil or criminal liability that might otherwise be imposed because of the release of what is otherwise confidential information.

As added by P.L. 2-1993, SEC.21.

# IC 16-38-2-9 Epidemiological information; release

Sec. 9 This chapter does not prevent the release to any interested person of epidemiological information that does not identify individual cancer patients.

As added by P.L. 2-1993, SEC.21.

#### IC 16-38-2-10 Administrative rules

Sec. 10. The state department shall adopt rules under IC 4-22-2 necessary to carry out this chapter.

As added by P.L. 2-1993, SEC.21.

# IC 16-38-2-11 Annual report

Sec. 11. Not later than December 31 of each year, the department shall publish and make available to the public an annual report summarizing the information collected under this chapter during the previous calendar year.

As added by P.L.93-2001, SEC.2. Amended by P.L. 17-2004, SEC.4.

#### **INDIANA ADMINISTRATIVE CODE - 410 IAC 21-1**

#### **ARTICLE 21. REPORTING**

# Rule 1. State Cancer Registry

#### 410 IAC 21-1-1 Definitions

Authority: IC 16-38-2-10 Affected: IC 16-38-2

Sec. 1. As used in 410 IAC 21-1:

"Cancer registry" means a mechanism by which data relating to all cases of malignant disease that occur in Indiana residents is recorded and, necessary and appropriate information is compiled concerning those cases as determined by the board, in order to conduct epidemiologic surveys of cancer and to apply appropriate preventive and control measures.

"Confirmed case" means the best evidence available for determining the nature of malignant disease using the following methods and codes: 1 = positive histology; 2 = positive exfoliative histology in the absence of positive histology; (3 is vacant) 4 = positive microscopic confirmation not otherwise specified (NOS); (5 is vacant) 6 = direct visualization without microscopic confirmation; 7 = radiography without microscopic confirmation; 8 = clinical diagnosis (other than 6 or 7) including gross examination at autopsy; and 9 = unspecified whether or not microscopically confirmed, unknown. This is a priority series with code 1 taking precedence. Each number takes priority over all higher numbers (i.e., 1 over 4, and 5 over 9 etc.).

"Data set" means all clinical, pathological [sic.,] therapeutic and demographic information defined in 410 IAC 21-1-4.

"ICD-O" means International Classification of Diseases for Oncology, 1976, World Health Organization publication, Organisation Mondiale De La Sante, 1211, Geneva 27, Switzerland.

"Indiana resident" means an individual domiciled in the state of Indiana.

"Malignant disease" means confirmed cases of cancer enumerated in the ICD-O excluding superficial, squamous and basal cell carcinomas of the skin.

"Patient" means any individual who is ill, or undergoing diagnosis or treatment for disease by a dentist, medical laboratory, physician or hospital.

"Person" means an individual, association, partnership, corporation, or governmental entity.

"State board" means the Indiana state board of health. (Indiana State Department of Health; 410 IAC 21-1-1; filed Nov 7, 1986, 3:30 pm: 10 IR 420; readopted filed Jul 11, 2001, 2:23 p.m.: 24 IR 4234)

# 410 IAC 21-1-2 General requirements

Authority: IC 16-38-2-10

Affected: IC 5-15-5.1-5; IC 16-38-2

Sec. 2. (a) All physicians, dentists, hospitals and medical laboratories shall report all confirmed cases of cancer occurring in Indiana residents who have been diagnosed or treated in Indiana, to the state board cancer registry.

(b) Any health care provider reporting to a public or private cancer registry on September 1, 1985 shall make available to the state cancer registry, all data as required under 410 IAC 21-1-3 (hospitals) or

- 410 IAC 21-1-4 (physicians, dentists and medical laboratories) upon the effective date of 410 IAC 21-1.
- (c) The state board shall assure state cancer registry computer compatibility for any health care provider who on or before the effective date of 410 IAC 21-1 elects to transmit the required data by way of a computerized mechanism.
- (d) Any health care provider who, after the effective date of 410 IAC 21-1, establishes a computerized mechanism for the purpose of transmitting abstracted data sets via computer link up, tape transfer, or direct interface, shall be responsible for assuring system compatibility with the state board cancer registry.
- (e) Any health care provider who elects to transfer abstracted data sets to the state cancer registry in paper form, shall utilize an abstract form designed or approved by the state board pursuant to IC 5-15-5.1-5.
- (f) All manually prepared data sets shall be mailed or delivered by the health care provider to the state cancer registry.
- (g) All health care providers not reporting to a public or private cancer registry on September 1, 1985, shall begin submitting data on cases diagnosed on or after January 1, 1987 to the state cancer registry as set out in 410 IAC 21-1-3 (hospitals) or 410 IAC 21-1-4 (physicians, dentists and medical laboratories), no later than six (6) months following the date of such diagnosis.
- (h) Reports of confirmed cases of malignant disease shall be submitted to the state cancer registry within six (6) months following a confirmed diagnosis. (Indiana State Department of Health; 410 IAC 21-1-2; filed Nov 7, 1986, 3:30 pm: 10 IR 420; readopted filed Jul 11, 2001, 2:23 p.m.: 24 IR 4234)

# 410 IAC 21-1-3 Hospitals

Authority: IC 16-38-2-10 Affected: IC 16-38-2

Sec. 3. (a) All hospitals shall submit abstracted data sets to the state board cancer registry which shall include but not be limited to the following data items:

- (1) site code
- (2) accession number
- (3) sequence number
- (4) accession year
- (5) social security number
- (6) medical record number
- (7) full name (including maiden name)
- (8) home address, city, county, state and zip code
- (9) phone number
- (10) date of birth
- (11) sex
- (12) race
- (13) class of case
- (14) admission date
- (15) follow-up physician
- (16) discharge date
- (17) date of initial diagnosis
- (18) topography code
- (19) paired organ involvement
- (20) histology code
- (21) tumor grade
- (22) diagnostic confirmation
- (23) tumor size (largest dimension)
- (24) number of positive nodes
- (25) number of nodes examined
- (26) sites of distant metastasis
- (27) general summary stage

- (28) TNM stage
- (29) AJCC stage group
- (30) TNM staging basis
- (31) date and method of first course of treatment
- (32) subsequent therapies/treatments (dates and methods)
- (b) Available updated information regarding all elements enumerated in 410 IAC 21-1-3(a) shall be reported to the state board cancer registry each twelve (12) month period following the initial reporting of the disease. (Indiana State Department of Health; 410 IAC 21-1-3; filed Nov 7, 1986, 3:30 pm: 10 IR 421; readopted filed Jul 11, 2001, 2:23 p.m.: 24 IR 4234)

# 410 IAC 21-1-4 Physicians, dentists and medical laboratories

Authority: IC 16-38-2-10 Affected: IC 16-38-2

Sec. 4. (a) Any physician, dentist or medical laboratory who diagnoses a case of malignant disease when such case is not referred to a hospital for further diagnosis or treatment, shall submit required data sets to the state cancer registry. Such data sets shall include but not be limited to the following available data items:

- (1) patient's full name (including maiden name)
- (2) patient's address (including city, county, state and zip code)
- (3) social security number
- (4) date of birth
- (5) sex
- (6) race
- (7) date of diagnosis
- (8) topography
- (9) morphology
- (10) diagnostic confirmation
- (11) hospital referred to
- (12) physician, dentist or laboratory license number
- (13) physician, dentist or laboratory name, address and phone number
- (b) Physicians, dentists and medical laboratories whose offices are located within the confines of a hospital or, who are employed or contracted by a hospital and who diagnose or treat patients for malignant disease, shall not be required to report cases of malignant disease under 410 IAC 21-1-4. Such cases shall be reported in accordance with 410 IAC 21-1-3. (Indiana State Department of Health; 410 IAC 21-1-4; filed Nov 7, 1986, 3:30 pm: 10 IR 421; readopted filed Jul 11, 2001, 2:23 p.m.: 24 IR 4234)

# 410 IAC 21-1-5 Security and confidentiality of data

Authority: IC 16-38-2-10

Affected: IC 5-14-3-10; IC 16-38-2

Sec. 5. (a) The state board shall assure confidentiality of patient record data when entering, retrieving, reviewing and utilizing such data.

- (b) The state board shall take all precautions and security measures necessary in order to protect the cancer registry data from intrusion or misuse by unauthorized individuals, and to preserve the right to privacy of individual patients maintained on the registry.
- (c) Pursuant to IC 5-14-3-10, any public employee or official, or any employee or officer of a contractor or subcontractor of a public agency who knowingly or intentionally discloses the identity of a patient maintained on the state cancer registry system to a person not authorized to receive such information, commits a Class A misdemeanor. Any public employee shall be disciplined in accordance with the personnel policies of the agency by which he is employed if he intentionally,

- knowingly, or recklessly discloses or fails to protect the identity of patients maintained on the state cancer registry system.
- (d) A person who reports information to the cancer registry system in accordance with 410 IAC 21-1, is immune from any civil or criminal liability that might otherwise be imposed because of release of what is otherwise confidential information. (Indiana State Department of Health; 410 IAC 21-1-5; filed Nov 7, 1986, 3:30 pm: 10 IR 422; readopted filed Jul 11, 2001, 2:23 p.m.: 24 IR 4234)

# 410 IAC 21-1-6 Cancer registry reports

Authority: IC 16-38-2-10 Affected: IC 16-38-2

- Sec. 6. (a) The state board shall make available to all hospitals licensed under IC 16-10-1 [IC 16-10 was repealed by P.L.2-1993, SECTION 209, effective April 30, 1993.], a comprehensive annual report which outlines the trends of malignant disease in Indiana and focuses on specific elements of special study regarding the disease.
- (b) Hospitals, physicians, dentists, laboratories and other persons may request and be provided with special reports from the state cancer registry, providing the data requested does not disclose the identity of a patient. (Indiana State Department of Health; 410 IAC 21-1-6; filed Nov 7, 1986, 3:30 pm: 10 IR 422; readopted filed Jul 11, 2001, 2:23 p.m.: 24 IR 4234)

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# Public Law 102-515 102d Congress

#### An Act

Oct. 24, 1992 [S. 3312] Entitled the "Cancer Registries Amendment Act."

Cancer
Registries
Amendment
Act.
Diseases.
Health and health
care.

42 USC 201 note.

42 USC 280e note.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

# SECTION 1. SHORT TITLE.

This Act may be cited as the "Cancer Registries Amendment Act." **SEC.2. FINDINGS AND PURPOSE** 

- (a) FINDINGS.-Congress finds that-
- (1) cancer control efforts, including prevention and early detection, are best addressed locally by State health departments that can identify unique needs;
- (2) cancer control programs and existing statewide population-based cancer registries have identified cancer incidence and cancer mortality rates that indicate the burden of cancer for Americans is substantial and varies widely by geographic location and by ethnicity;
- (3) Statewide cancer incidence and cancer mortality data, can be used to identify cancer trends, patterns, and variation for directing cancer control intervention:
- (4) the American Association of Central Cancer Registries (AACCR) cites that of the 50 States, approximately 38 have established cancer registries, many are not statewide and 10 have no cancer registry; and
- (5) AACCR also cites that of the 50 States, 39 collect data on less than 100 percent of their population, and less than half have adequate resources for insuring minimum standards for quality and for completeness of case information.
- (b) PURPOSE.-It is the purpose of this Act to establish a national program of cancer registries.

# SEC. 3. NATIONAL PROGRAM OF CANCER REGISTRIES.

Title III of the Public Health Service Act (42 U.S.C. 241 et seq.) is amended by adding at the end the following new part:

"PART M-NATIONAL PROGRAM OF CANCER REGISTRIES" "SEC. 399H. NATIONAL PROGRAM OF CANCER REGISTRIES.

"(a) IN GENERAL.-The Secretary, acting through the Director of the Centers for Disease Control, may make grants to States, or may make grants or enter into contracts with academic or nonprofit organizations designated by the State to operate the State's cancer registry in lieu of making a grant directly to the State, to support the operation of population-based, statewide cancer registries in order to collect, for each form of in-situ and invasive cancer (with the exception of basal cell and squamous cell carcinoma of the

skin), data concerning-

42 USC 280e.

- "(1) demographic information about each case of cancer;
- "(2) information on the industrial or occupational history of the individuals with the cancers, to the extent such information is available from the same record;
- "(3) administrative information, including date of diagnosis and source of information;
- "(4) pathological data characterizing the cancer, including the cancer site, stage of disease (pursuant to Staging Guide), incidence, and type of treatment; and
  - "(5) other elements determined appropriate by the Secretary.
  - "(b) MATCHING FUNDS.-
- "(1) IN GENERAL.-The Secretary may make a grant under subsection (a) only if the State, or the academic or nonprofit private organization designated by the State to operate the cancer registry of the State, involved agrees, with respect to the costs of the program, to make available (directly or through donations from public or private entities) non-Federal contributions toward such costs in an amount that is not less than 25 percent of such costs or \$1 for every \$3 of Federal funds provided in the grant.
- "(2) DETERMINATION OF AMOUNT OF NON-FEDERAL CONTRIBUTION: MAINTENANCE OF EFFORT.-
  - "(A) Non-Federal contributions required in paragraph (1) may be in cash or in kind, fairly evaluated, including plant, equipment, or services. Amounts provided by the Federal Government, or services assisted or subsidized to any significant extent by the Federal Government, may not be included in determining the amount of such non-Federal contributions.
- "(B) With respect to a State in which the purpose described in subsection (a) is to be carried out, the Secretary, in making a determination of the amount of non-Federal contributions provided under paragraph (1), may include only such contributions as are in excess of the amount of such contributions made by the State toward the collection of data on cancer for the fiscal year preceding the first year for which a grant under subsection (a) is made with respect to the State. The Secretary may decrease the amount of non-Federal contributions that otherwise would have been required by this subsection in those cases in which the State can demonstrate that decreasing such amount is appropriate because of financial hardship. "(c) ELIGIBILITY FOR GRANTS.-
- "(1) IN GENERAL.-No grant shall be made by the Secretary under subsection (a) unless an application has been submitted to, and approved by, the Secretary. Such application shall be in such form, submitted in such a manner, and be accompanied by such information, as the Secretary may specify. No such application may be approved unless it contains assurances that the applicant will use the funds provided only for the

purposes specified in the approved application and in accordance with the requirements of this section, that the application will establish such fiscal control and fund accounting procedures as may be necessary to assure proper disbursement and accounting of Federal funds paid to the applicant under subsection (a) of this section, and that the applicant will comply with the peer review requirements under sections 491 and 492.

- "(2) ASSURANCES.-Each applicant, prior to receiving Federal funds under subsection (a), shall provide assurances satisfactory to the Secretary that the applicant will-
  - "(A) provide for the establishment of a registry in accordance with subsection (a);
  - "(B) comply with appropriate standards of completeness, timeliness, and quality of population-based cancer registry data;
  - "(C) provide for the annual publication of reports of cancer data under subsection (a); and
  - "(D) provide for the authorization under State law of the statewide cancer registry, including promulgation of regulations providing-
    - "(i) a means to assure complete reporting of cancer cases (as described in subsection (a)) to the statewide cancer registry by hospitals or other facilities providing screening, diagnostic or therapeutic services to patients with respect to cancer;
    - "(ii) a means to assure the complete reporting of cancer cases (as defined in subsection (a)) to the statewide cancer registry by physicians, surgeons, and all other health care practitioners diagnosing or providing treatment for cancer patients, except for cases directly referred to or previously admitted to a hospital or other facility providing screening, diagnostic or therapeutic services to patients in that State and reported by those facilities;
    - "(iii) a means for the statewide cancer registry to access all records of physicians and surgeons, hospitals, outpatient clinics, nursing homes, and all other facilities, individuals, or agencies providing such services to patients which would identify cases of cancer or would establish characteristics of the cancer, treatment of the cancer, or medical status of any identified patient;
    - "(iv) for the reporting of cancer case data to the statewide cancer registry in such a format, with such data elements, and in accordance with such standards of quality timeliness and completeness, as may be established by the Secretary;
    - "(v) for the protection of the confidentiality of all cancer case data reported to the statewide cancer registry, including a prohibition on disclosure to any person of information reported to the statewide cancer registry that identifies, or could lead to the identification of, an individual cancer patient, except for disclosure to other State cancer registries and local and State health officers:

"(vi) for a means by which confidential case data may in accordance with State law be disclosed to cancer researchers for the purposes of cancer prevention, control and research;

"(vii) for the authorization or the conduct, by the statewide cancer registry or other persons and organizations, of studies utilizing statewide cancer registry data, including studies of the sources and causes of cancer, evaluations of the cost, quality, efficacy, and appropriateness of diagnostic, therapeutic, rehabilitative, and preventative services and programs relating to cancer, and any other clinical, epidemiological, or other cancer research; and

"(viii) for protection for individuals complying with the law, including provisions specifying that no person shall be held liable in any civil action with respect to a cancer case report provided to the statewide cancer registry, or with respect to access to cancer case information provided to the statewide cancer registry.

# "(d) RELATIONSHIP TO CERTAIN PROGRAMS.-

- "(1) IN GENERAL.-This section may not be construed to act as a replacement for or diminishment of the program carried out by the Director of the National Cancer Institute and designated by such Director as the Surveillance, Epidemiology, and End Results Program (SEER).
- "(2) SUPPLANTING OF ACTIVITIES.-In areas where both such programs exist, the Secretary shall ensure that SEER support is not supplanted and that any additional activities are consistent with the guidelines provided for in subsection (c)(2) (C) and (D) and are appropriately coordinated with the existing SEER program.
- "(3) TRANSFER OF RESPONSIBILITY.- The Secretary may not transfer administration responsibility for such SEER program from such Director.
- "(4) COORDINATION.-To encourage the greatest possible efficiency and effectiveness of Federally supported efforts with respect to the activities described in this subsection, the Secretary shall take steps to assure the appropriate coordination of programs supported under this part with existing Federally supported cancer registry programs.
- "(e) REQUIREMENT REGARDING CERTAIN STUDY ON BREAST CANCER.-In the case of a grant under subsection (a) to any State specified in section 399K(b), the Secretary may establish such conditions regarding the receipt of the grant as the Secretary determines are necessary to facilitate the collection of data for the study carried out under section 399C.

# "SEC. 399I. PLANNING GRANTS REGARDING REGISTRIES.

"(a) IN GENERAL.-

"(1) STATES.-The Secretary, acting through the Director of the Centers for Disease Control, may make grants to States for the purpose of developing plans that meet the assurances required by the Secretary under section 399B(c)(2).

42 USC 280e-1.

"(2) OTHER ENTITIES.-For the purpose described in paragraph (1), the Secretary may make grants to public entities other than States and to nonprofit private entities. Such a grant may be made to an entity only if the State in which the purpose is to be carried out has certified that the State approves the entity as qualified to carry out the purpose.

"(b) APPLICATION.-The Secretary may make a grant under subsection (a) only if an application for the grant is submitted to the Secretary, the application contains the certification required in subsection (a)(2) (if the application is for a grant under such subsection), and the application is in such form, is made in such manner, and contains such agreements, assurances, and information as the Secretary determines to be necessary to carry out this section.

42 USC 280e-2.

# "SEC. 399J. TECHNICAL ASSISTANCE IN OPERATIONS OF STATEWIDE CANCER REGISTRIES.

"The Secretary, acting through the Director of the Centers for Disease Control, may, directly or through grants and contracts, or both, provide technical assistance to the States in the establishment and operation of statewide registries, including assistance in the development of model legislation for statewide cancer registries and assistance in establishing a computerized reporting and data processing system.

42 USC 280e-3.

# "SEC. 399K. STUDY IN CERTAIN STATES TO DETERMINE THE FACTORS CONTRIBUTING TO THE ELEVATED BREAST CANCER MORTALITY RATES.

- "(a) IN GENERAL.-Subject to subsections (c) and (d), the Secretary, acting through the Director of the National Cancer Institute, shall conduct a study for the purpose of determining the factors contributing to the fact that breast cancer mortality rates in the States specified in subsection (b) are elevated compared to rates in other States.
- "(b) RELEVANT STATES.-The States referred to in subsection (a) are Connecticut, Delaware, Maryland, Massachusetts, New Hampshire, New Jersey, New York, Rhode Island, Vermont, and the District of Columbia.
- "(c) COOPERATION OF STATE.-The Secretary may conduct the study required in subsection (a) in a State only if the State agrees to cooperate with the Secretary in the conduct of the study, including providing information from any registry operated by the State pursuant to section 399H(a).
- "(d) PLANNING, COMMENCEMENT, AND DURATION.-The Secretary shall, during each of the fiscal years 1993 and 1994, develop a plan for conducting the study required in subsection (a). The study shall be initiated by the Secretary not later than fiscal year 1994, and the collection of data under the study may continue through fiscal year 1998.
- "(e) REPORT.-Not later than September 30, 1999, the Secretary shall complete the study required in subsection (a) and submit to the Committee on Energy and Commerce of the House of Representatives, and to the Committee on Labor and Human Resources of the Senate, a report describing the findings and recommendations made as a result of the study.

# "SEC. 399L. AUTHORIZATION OF APPROPRIATIONS.

42 USC 280e-4.

- "(a) REGISTRIES.-For the purpose of carrying out this part, the Secretary may use \$30,000,000 for each of the fiscal years 1993 through 1997. Out of any amounts used for any such fiscal year, the Secretary may obligate not more than 25 percent for carrying out section 399I, and not more than 10 percent may be expended for assessing the accuracy, completeness and quality of data collected, and not more than 10 percent of which is to be expended under subsection 399J.
- "(b) BREAST CANCER STUDY.-Of the amounts appropriated for the National Cancer Institute under subpart 1 of part C of title IV for any fiscal year in which the study required in section 399K is being carried out, the Secretary shall expend not less than \$1,000,000 for the study."

Approved October 24, 1992.

Authorization extended through 1998.

#### **Public Law 107-260**

# Benign Brain Tumor Cancer Registries Amendment Act

# **SECTION 1. SHORT TITLE.**

This Act may be cited as the "Benign Brain Tumor Cancer Registries Amendment Act."

# SEC. 2. NATIONAL PROGRAM OF CANCER REGISTRIES; BENIGN BRAIN-RELATED TUMORS AS ADDITIONAL CATEGORY OF DATA COLLECTED.

- (a) IN GENERAL- Section 399B of the Public Health Service Act (42 U.S.C. 280e), as redesignated by section 502(2)(A) of Public Law 106-310 (114 Stat. 1115), is amended in subsection (a)--
  - (1) by redesignating paragraphs (1) through (5) as subparagraphs (A) through (E), respectively, and indenting appropriately;
- (2) by striking "(a) IN GENERAL- The Secretary" and inserting the following: (a) IN GENERAL-
  - (1) STATEWIDE CANCER REGISTRIES- The Secretary;
  - (3) in the matter preceding subparagraph (A) (as so redesignated), by striking "population-based" and all that follows through "data" and inserting the following: population-based, statewide registries to collect, for each condition specified in paragraph (2)(A), data; and
  - (4) by adding at the end the following:
  - (2) CANCER; BENIGN BRAIN-RELATED TUMORS-
    - (A) IN GENERAL- For purposes of paragraph (1), the conditions referred to in this paragraph are the following:
      - (i) Each form of in-situ and invasive cancer (with the exception of basal cell and squamous cell carcinoma of the skin), including malignant brain-related tumors.
      - (ii) Benign brain-related tumors.
    - (B) BRAIN-RELATED TUMOR- For purposes of subparagraph (A):
      - (i) The term "brain-related tumor" means a listed primary tumor (whether malignant or benign) occurring in any of the following sites:
        - (I) The brain, meninges, spinal cord, cauda equina, a cranial nerve or nerves, or any other part of the central nervous system.
        - (II) The pituitary gland, pineal gland, or craniopharyngeal duct.
      - (ii) The term "listed," with respect to a primary tumor, means a primary tumor that is listed in the International Classification of Diseases for Oncology (commonly referred to as the ICD-O).
      - (iii) The term "International Classification of Diseases for Oncology" means a classification system that includes topography (site) information and histology (cell type information) developed by the World Health Organization, in collaboration with international

centers, to promote international comparability in the collection, classification, processing, and presentation of cancer statistics. The ICD-O system is a supplement to the International Statistical Classification of Diseases and Related Health Problems (commonly known as the ICD) and is the standard coding system used by cancer registries worldwide. Such term includes any modification made to such system for purposes of the United States. Such term further includes any published classification system that is internationally recognized as a successor to the classification system referred to in the first sentence of this clause.

- (C) STATEWIDE CANCER REGISTRY- References in this section to cancer registries shall be considered to be references to registries described in this subsection.
- (b) APPLICABILITY- The amendments made by subsection (a) apply to grants under section 399B of the Public Health Service Act for fiscal year 2002 and subsequent fiscal years, except that, in the case of a State that received such a grant for fiscal year 2000, the Secretary of Health and Human Services may delay the applicability of such amendments to the State for not more than 12 months if the Secretary determines that compliance with such amendments requires the enactment of a statute by the State or the issuance of State regulations.

# APPENDIX B: REPORTABLE LIST

The definitions in the State Cancer Registry Policy and Procedure Manual describe reportable cases in terms of their *ICD-O-3* topography and morphology codes. These pages contain all reportable malignancies with an *International Classification of Diseases of Oncology*, Third Edition (*ICD-O-3*) behavior code of /2 or /3. Diagnoses with a behavior code of /0 (benign) or /1 (borderline) are not reportable to the State Cancer Registry except for intracranial and central nervous tumors diagnosed 01/01/2004 and later. See section B of this appendix for the reportable list of benign and borderline intracranial and central nervous tumors.

#### A. REPORTABLE MALIGNANCIES

Conditions are to be reported if the diagnosis includes the words:

Cancer

Carcinoma (except certain basal or squamous cell carcinomas of the skin, CIS, CIN III, and PIN III, as described in Chapter 3)

Leukemia Lymphoma

Malignant

Melanoma

Sarcoma

The following terms, used as adjectives, are also to be reported when used in the description of a malignancy:

Anaplastic

Histiocytic

Intraepithelial

Keratinizing

Medullary

Moderately differentiated

Non-keratinizing

Poorly differentiated

Small cell

Well differentiated

The morphologic terms listed below are malignancies and should be reported. Changes in *ICD-O-3* are identified by special formatting that is explained below.

- <u>Underlined terms</u> represent new morphology terms and synonyms in *ICD-O-3*. Some, but not all, of the underlined terms have new *ICD-O-3* codes associated with them.
- <u>Highlighted items</u> are terms that changed from borderline in *ICD-O-2* to malignant in *ICD-O-3* and are reportable if diagnosed on or after January 1, 2001.
- A strikethrough indicates the term was changed from malignant in *ICD-O-2* to borderline in *ICD-O-3* and is not reportable if diagnosed on or after January 1, 2001.
- [obs] designates terminology that is identified as obsolete in *ICD-O-3*.

-A-

Acidophil adenocarcinoma
Acidophil carcinoma
Acinar adenocarcinoma
Acinar carcinoma
Acinar cell carcinoma
Acinar cell cystadenocarcinoma
Acinic cell adenocarcinoma
Acral lentiginous melanoma, malignant

Acute basophilic leukemia
Acute bilineal leukemia
Acute biphenotypic leukemia
Acute differentiated progressive histiocytosis
(See acute progressive histiocytosis X)
Acute erythremia [obs]
Acute erythremic myelosis [obs]
Acute erythroid leukemia
Acute granulocytic leukemia, minimal differentiation

Reportable List Appendix B

Acute granulocytic leukemia (FAB or WHO type not Acute myelomonocytic leukemia, NOS specified) Acute myelomonocytic leukemia with abnormal Acute granulocytic leukemia with maturation eosinophils Acute granulocytic leukemia without maturation Acute myelosclerosis Acute leukemia, Burkitt type [obs] Acute non-lymphocytic leukemia Acute leukemia, NOS Acute panmyelosis, NOS [obs] Acute lymphatic leukemia Acute panmyelosis with myelofibrosis Acute lymphatic leukemia, L1 type Acute progressive histiocytosis X Acute lymphatic leukemia, L2 type Acute promyelocytic leukemia, NOS Acute lymphoblastic leukemia, Burkitt type Acute promyelocytic leukemia, PML/RAR-alpha Acute lymphoblastic leukemia, L1 type, NOS Acute promyelocytic leukemia, t(15;17)(q22;q11-12) Adamantinoma, malignant Acute lymphoblastic leukemia, L2 type, NOS Acute lymphoblastic leukemia, mature B-cell type Adamantinoma of long bones Acute lymphoblastic leukemia, NOS Adenoacanthoma Acute lymphoblastic leukemia, precursor-cell type Adenocarcinoid tumor Acute lymphoblastic leukemia-lymphoma, NOS Adenocarcinoma combined with other types of Acute lymphocytic leukemia carcinoma Acute lymphocytic leukemia, L1 type Adenocarcinoma, cylindroid Acute lymphocytic leukemia, L2 type Adenocarcinoma, diffuse type Acute lymphoid leukemia Adenocarcinoma, endocervical type Acute lymphoid leukemia, L1 type Adenocarcinoma in a polyp, NOS Acute lymphoid leukemia, L2 type Adenocarcinoma in adenomatous polyp Acute megakaryoblastic leukemia Adenocarcinoma in adenomatous polyposis coli Acute mixed lineage leukemia Adenocarcinoma in multiple adenomatous polyps Acute monoblastic leukemia Adenocarcinoma in polypoid adenoma Acute monocytic leukemia Adenocarcinoma in situ in a polyp, NOS Acute myeloblastic leukemia, minimal differentiation Adenocarcinoma in situ in adenomatous polyp Acute myeloblastic leukemia Adenocarcinoma in situ in polypoid adenoma Acute myeloblastic leukemia with maturation Adenocarcinoma in situ in tubular adenoma Acute myeloblastic leukemia without maturation Adenocarcinoma in situ in tubulovillous adenoma Acute myelocytic leukemia, minimal differentiation Adenocarcinoma in situ in villous adenoma Acute myelocytic leukemia (FAB or WHO type not Adenocarcinoma in situ. NOS specified) Adenocarcinoma in tubular adenoma Acute myelocytic leukemia with maturation Adenocarcinoma in tubulovillous adenoma Acute myelocytic leukemia without maturation Adenocarcinoma in villous adenoma Acute myelofibrosis Adenocarcinoma, intestinal type Acute myelogenous leukemia, minimal differentiation Adenocarcinoma, NOS Adenocarcinoma of anal ducts Acute myelogenous leukemia (FAB or WHO type not specified) Adenocarcinoma of anal glands Acute myelogenous leukemia with maturation Adenocarcinoma with apocrine metaplasia Acute myelogenous leukemia without maturation Adenocarcinoma with cartilaginous and osseous Acute myeloid leukemia, minimal differentiation metaplasia Acute myeloid leukemia, NOS Adenocarcinoma with cartilaginous metaplasia Adenocarcinoma with mixed subtypes Acute myeloid leukemia with abnormal marrow eosinophils (includes all variants) Adenocarcinoma with neuroendocrine differentiation Adenocarcinoma with osseous metaplasia Acute myeloid leukemia with maturation Adenocarcinoma with spindle cell metaplasia Acute myeloid leukemia with multilineage dysplasia Acute myeloid leukemia with prior myelodysplastic Adenocarcinoma with squamous metaplasia Adenocystic carcinoma syndrome Acute myeloid leukemia without maturation Adenoid basal carcinoma Acute myeloid leukemia without prior myelodysplastic Adenoid cystic carcinoma syndrome Adenoid squamous cell carcinoma Acute myeloid leukemia, 11q23 abnormalities Adenosarcoma Acute myeloid leukemia, AML1(CBF-alpha)/ETO Adenosquamous carcinoma Adnexal carcinoma Acute myeloid leukemia, CBF-beta/MYH11 Acute myeloid leukemia, inv(16)(p13;q22) Adrenal cortical adenocarcinoma Acute myeloid leukemia, M6 type Adrenal cortical carcinoma Acute myeloid leukemia, MLL Adrenal cortical tumor, malignant Acute myeloid leukemia, PML/RAR-alpha Adrenal medullary paraganglioma, malignant

Acute myeloid leukemia, t(8;21)(q22;q22) Acute myeloid leukemia, t(15;17)(q22;q11-12)

Acute myeloid leukemia, t(16;16)(p13;q11)

Adult T-cell leukemia

Adult T-cell leukemia/lymphoma

Appendix B Reportable List

Adult T-cell leukemia/lymphoma (HTLV-1 positive) (includes all variants) -B-Adult T-cell lymphoma B-ALL [obs] Adult T-cell lymphoma/leukemia Balloon cell melanoma Aggressive NK-cell leukemia **BALT** lymphoma Agnogenic myeloid metaplasia Basal cell adenocarcinoma AIN III Basaloid carcinoma Aleukemic granulocytic leukemia [obs] Basaloid squamous cell carcinoma Aleukemic leukemia, NOS [obs] Basophil adenocarcinoma Aleukemic lymphatic leukemia [obs] Basophil carcinoma Aleukemic lymphocytic leukemia [obs] Basophilic leukemia Aleukemic lymphoid leukemia [obs] Aleukemic monocytic leukemia [obs] lymphoma Aleukemic myelogenous leukemia [obs] B-cell lymphoma, NOS Aleukemic myeloid leukemia [obs] Bednar tumor

Alpha cell tumor, malignant Alpha heavy chain disease Alveolar adenocarcinoma Alveolar carcinoma Alveolar cell carcinoma Alveolar rhabdomyosarcoma Alveolar soft part sarcoma Amelanotic melanoma Ameloblastic carcinoma

Ameloblastic fibrodentinosarcoma Ameloblastic fibro-odontosarcoma Ameloblastic fibrosarcoma Ameloblastic odontosarcoma Ameloblastic sarcoma

Ameloblastoma, malignant AML M6

Anal intraepithelial neoplasia, grade III Anaplastic large B-cell lymphoma

Anaplastic large cell lymphoma (ALCL), CD 30+

Anaplastic large cell lymphoma, NOS

Anaplastic large cell lymphoma, T cell and Null cell type

Anaplastic oligoastrocytoma Androblastoma, malignant

Angiocentric T-cell lymphoma [obs]

Angioendotheliomatosis

Angioimmunoblastic lymphoma [obs] Angioimmunoblastic T-cell lymphoma

Angiomyosarcoma Angiosarcoma Angiotropic lymphoma Apocrine adenocarcinoma Argentaffinoma, malignant [obs]

Arrhenoblastoma, malignant Askin tumor Astroblastoma Astrocytic glioma Astrocytoma, anaplastic

Astrocytoma, low grade Astrocytoma, NOS Astroglioma [obs]

Atypical carcinoid tumor

Atypical chronic myeloid leukemia, BCR/ABL negative Atypical chronic myeloid leukemia, Philadelphia

chromosome (Ph1) negative Atypical medullary carcinoma

Atypical proliferative papillary serous tumor

Atypical teratoid/rhabdoid tumor

B-cell chronic lymphocytic leukemia/small lymphocytic

Bellini duct carcinoma Beta cell tumor, malignant Bile duct adenocarcinoma

Bile duct carcinoma

Bile duct cystadenocarcinoma

Blast cell leukemia Blastoma, NOS Blue nevus, malignant Botryoid sarcoma Brenner tumor, malignant Bronchial adenoma, carcinoid

Bronchial adenoma, cylindroid [obs]

Bronchial-associated lymphoid tissue lymphoma

Bronchiolar adenocarcinoma Bronchiolar carcinoma

Bronchiolo-alveolar adenocarcinoma, NOS Bronchiolo-alveolar carcinoma. NOS Bronchiolo-alveolar carcinoma, Clara cell

Bronchiolo-alveolar carcinoma, Clara cell and goblet cell

Bronchiolo-alveolar carcinoma, goblet cell type Bronchiolo-alveolar carcinoma, indeterminate type Bronchiolo-alveolar carcinoma, mixed mucinous and

non-mucinous

Bronchiolo-alveolar carcinoma, mucinous Bronchiolo-alveolar carcinoma, non-mucinous Bronchiolo-alveolar carcinoma, type II pneumocyte Bronchiolo-alveolar carcinoma, type II pneumocyte and

goblet cell type Burkitt cell leukemia Burkitt-like lymphoma Burkitt lymphoma, NOS Burkitt tumor [obs]

-C-

C cell carcinoma

C-ALL Cancer

Carcinofibroma

Carcinoid, NOS (except appendix) Carcinoid tumor, argentaffin, malignant Carcinoid tumor, NOS (except appendix)

Carcinoma, anaplastic, NOS Carcinoma, diffuse type Carcinoma in a polyp, NOS Carcinoma in adenomatous polyp Reportable List Appendix B

Carcinoma in pleomorphic adenoma Carcinoma in situ in a polyp, NOS Carcinoma in situ in adenomatous polyp

Carcinoma in situ, NOS Carcinoma, intestinal type

Carcinoma, NOS

Carcinoma showing thymus-like differentiation

Carcinoma showing thymus-like element

Carcinoma simplex

Carcinoma, undifferentiated, NOS Carcinoma with apocrine metaplasia

Carcinoma with neuroendocrine differentiation

Carcinoma with osteoclast-like giant cells

Carcinoma with productive fibrosis

Carcinosarcoma, embryonal Carcinosarcoma, NOS

CASTLE

Cellular ependymoma

Central neuroblastoma

Central osteosarcoma

Central primitive neuroectodermal tumor, NOS

Cerebellar sarcoma, NOS [obs] Ceruminous adenocarcinoma

Ceruminous carcinoma

Chloroma

Cholangiocarcinoma

Chondroblastic osteosarcoma Chondroblastoma, malignant

<u>Chondroid</u> <u>chordoma</u> Chondrosarcoma, NOS

Chondrosarcoma, NOS Chordoma, NOS

Choriocarcinoma combined with embryonal carcinoma

Choriocarcinoma combined with other germ cell elements

Choriocarcinoma combined with teratoma

Choriocarcinoma, NOS Chorioepithelioma Chorionepithelioma Choroid plexus carcinoma

Choroid plexus papilloma, anaplastic Choroid plexus papilloma, malignant Chromophobe adenocarcinoma

Chromophobe carcinoma

<u>Chromophobe cell renal carcinoma</u> <u>Chronic eosinophilic leukemia</u>

Chronic erythremia [obs]

Chronic granulocytic leukemia

Chronic granulocytic leukemia, BCR/ABL Chronic granulocytic leukemia, Philadelphia

chromosome (Ph1) positive

Chronic granulocytic leukemia, t(9;22)(q34;q11)

Chronic idiopathic myelofibrosis Chronic leukemia, NOS [obs] Chronic lymphatic leukemia Chronic lymphocytic leukemia

Chronic lymphocytic leukemia, B-cell type (includes all

variants of BCLL)
Chronic lymphoid leukemia
Chronic monocytic leukemia [obs]
Chronic myelocytic leukemia

Chronic myelogenous leukemia, BCR/ABL positive

Chronic myelogenous leukemia, Philadelphia

chromosome (Ph1) positive

Chronic myelogenous leukemia, t(9;22)(q34;q11)

Chronic myelogenous leukemia Chronic myeloid leukemia

<u>Chronic myelomonocytic leukemia in transformation</u>

[obs]

Chronic myelomonocytic leukemia, NOS Chronic myelomonocytic leukemia, Type I Chronic myelomonocytic leukemia, Type 2 Chronic myeloproliferative disease, NOS

Chronic myeloproliferative disorder

Chronic neutrophilic leukemia

Circumscribed arachnoidal cerebellar sarcoma [obs]
Classical Hodgkin lymphoma, lymphocyte depletion,
diffuse fibrosis

<u>Classical Hodgkin lymphoma, lymphocyte depletion,</u> NOS

<u>Classical Hodgkin lymphoma, lymphocyte depletion, reticular</u>

Classical Hodgkin lymphoma, lymphocyte-rich

Classical Hodgkin lymphoma, mixed cellularity, NOS Classical Hodgkin lymphoma, nodular sclerosis, cellular

<u>phase</u>

Classical Hodgkin lymphoma, nodular sclerosis, grade 1 Classical Hodgkin lymphoma, nodular sclerosis, grade 2 Classical Hodgkin lymphoma, nodular sclerosis, NOS

Clear cell adenocarcinofibroma

Clear cell adenocarcinoma, mesonephroid

Clear cell adenocarcinoma, NOS

Clear cell carcinoma Clear cell chondrosarcoma

Clear cell cystadenocarcinofibroma

Clear cell ependymoma
Clear cell sarcoma, NOS
Clear cell sarcoma of kidney

Clear cell sarcoma, of tendons and aponeuroses

Cloacogenic carcinoma
Collecting duct carcinoma
Colloid adenocarcinoma
Colloid carcinoma

Combined carcinoid and adenocarcinoma Combined hepatocellular carcinoma and

cholangiocarcinoma

<u>Combined small cell carcinoma</u>

<u>Combined small cell-adenocarcinoma</u>

<u>Combined small cell-large cell carcinoma</u>

<u>Combined small cell-squamous cell carcinoma</u>

Comedocarcinoma, noninfiltrating

Comedocarcinoma, NOS

Common ALL

Common precursor B ALL Composite carcinoid

Composite Hodgkin and non-Hodgkin lymphoma

Condylomatous carcinoma Congenital fibrosarcoma

Conventional central osteosarcoma

Cortical T ALL CPNET

Cribriform carcinoma, NOS Cribriform carcinoma in situ Cutaneous lymphoma, NOS [obs] Appendix B Reportable List

Cutaneous T-cell lymphoma, NOS

Cylindrical cell carcinoma

Cylindroma, NOS (except Cylindroma of skin M-8200/0)

Cystadenocarcinoma, NOS

Cyst-associated renal cell carcinoma

Cystic astrocytoma [obs]

Cystic hypersecretory carcinoma

Cystosarcoma phyllodes, malignant

#### -D-

DCIS, comedo type

DCIS, NOS

DCIS, papillary

Dedifferentiated chondrosarcoma

**Dedifferentiated** chordoma

Dedifferentiated liposarcoma

Dendritic cell sarcoma, NOS

Dermatofibrosarcoma, NOS

Dermatofibrosarcoma protuberans, NOS

Dermoid cyst with malignant transformation

Dermoid cyst with secondary tumor

Desmoplastic medulloblastoma

Desmoplastic melanoma, amelanotic

Desmoplastic melanoma, malignant

Desmoplastic mesothelioma

Desmoplastic nodular medulloblastoma

Desmoplastic small round cell tumor

Di Guglielmo disease [obs]

Diffuse astrocytoma

Diffuse astrocytoma, low grade

Digital papillary adenocarcinoma

Diktyoma, malignant

DIN 3

Duct adenocarcinoma, NOS

Duct carcinoma, desmoplastic type

Duct carcinoma, NOS

Duct cell carcinoma

Ductal carcinoma, NOS

Ductal carcinoma in situ, comedo type

Ductal carcinoma in situ, cribriform type

Ductal carcinoma in situ, micropapillary

Ductal carcinoma in situ, NOS

Ductal carcinoma in situ, papillary

Ductal carcinoma in situ, solid type

Ductal carcinoma, cribriform type

Ductal intraepithelial neoplasia 3

Dysgerminoma

#### -E-

EC cell carcinoid

Eccrine adenocarcinoma

Eccrine papillary adenocarcinoma

Eccrine poroma, malignant

ECL cell carcinoid, malignant

Ectomesenchymoma

Embryonal adenocarcinoma

Embryonal carcinoma, infantile

Embryonal carcinoma, NOS

Embryonal carcinoma, polyembryonal type

Embryonal hepatoma

Embryonal rhabdomyosarcoma, NOS

Embryonal rhabdomyosarcoma, pleomorphic

Embryonal sarcoma

Embryonal teratoma

Endodermal sinus tumor

Endolymphatic stromal myosis

Endometrial sarcoma, NOS

Endometrial stromal sarcoma, NOS

Endometrial stromal sarcoma, high grade

Endometrial stromal sarcoma, low grade

Endometrial stromatosis

Endometrioid adenocarcinoma, NOS

Endometrioid adenocarcinoma, ciliated cell variant

Endometrioid adenocarcinoma, secretory variant

Endometrioid adenofibroma, malignant

Endometrioid carcinoma, NOS

Endometrioid cystadenocarcinoma

Endometrioid cystadenofibroma, malignant

Enterochromaffin cell carcinoid

Enterochromaffin-like cell tumor, malignant

Enteroglucagonoma, malignant

Enteropathy associated T-cell lymphoma

Enteropathy type intestinal T-cell lymphoma

Eosinophil adenocarcinoma

Eosinophil carcinoma

Eosinophilic leukemia

Ependymoblastoma

Ependymoma, anaplastic

Ependymoma, NOS

Epidermoid carcinoma in situ, NOS

Epidermoid carcinoma in situ with questionable stromal

invasion

Epidermoid carcinoma, keratinizing

Epidermoid carcinoma, large cell, nonkeratinizing

Epidermoid carcinoma, NOS

Epidermoid carcinoma, small cell, nonkeratinizing

Epidermoid carcinoma, spindle cell

Epithelial ependymoma

Epithelial tumor, malignant

Epithelial-myoepithelial carcinoma

Epithelioid cell melanoma

Epithelioid cell sarcoma

Epithelioid hemangioendothelioma, malignant

Epithelioid leiomyosarcoma

Epithelioid mesothelioma, malignant

Epithelioid mesothelioma, NOS

Epithelioid MPNST

Epithelioid sarcoma

Epithelioma, malignant

Epithelioma, NOS

Erythremic myelosis, NOS [obs]

Ervthroleukemia

Essential hemorrhagic thrombocythemia

Essential thrombocythemia

Esthesioneuroblastoma Esthesioneurocytoma

Esthesioneuroepithelioma

Ewing sarcoma

Ewing tumor

Extra-adrenal paraganglioma, malignant

Extramedullary plasmacytoma

Reportable List Appendix B

-F-Germ cell tumor, nonseminomatous Germ cell tumor, NOS FAB L1 [obs] Germinoma FAB L2 Giant cell and spindle cell carcinoma FAB L3 [obs] Giant cell carcinoma FAB M0 Giant cell glioblastoma FAB M1 Giant cell sarcoma FAB M2, AML1(CBF-alpha)/ETO Giant cell sarcoma of bone FAB M2, NOS Giant cell tumor of bone, malignant FAB M2, t(8;21)(q22;q22) Giant cell tumor of tendon sheath, malignant FAB M3 (includes all variants) GIST, malignant FAB M4 Glandular intraepithelial neoplasia, grade III FAB M4Eo (replaced ICD-O-2's FAB M4E in ICD-O-3) Glassy cell carcinoma FAB M5 (includes all variants) (replaced ICD-O-2's Glioblastoma multiforme entries for FAB M5A and FAB M5B in ICD-O-3) Glioblastoma, NOS FAB M6 Glioblastoma with sarcomatous component FAB M7 Glioma, malignant Fascial fibrosarcoma Glioma, NOS Fetal adenocarcinoma Gliomatosis cerebri Fibrillary astrocytoma Gliosarcoma Fibroblastic liposarcoma Glomangiosarcoma Fibroblastic osteosarcoma Glomoid sarcoma Fibrochondrosarcoma Glomus tumor, malignant Fibroepithelial basal cell carcinoma, Pinkus type Glucagonoma, malignant Fibroepithelioma of Pinkus type Glycogen-rich carcinoma Fibroepithelioma, NOS Goblet cell carcinoid Fibroliposarcoma Granular cell adenocarcinoma Fibromyxosarcoma Granular cell carcinoma Fibrosarcoma, NOS Granular cell myoblastoma, malignant Fibrous astrocytoma Granular cell tumor, malignant Fibrous histiocytoma, malignant Granulocytic leukemia, NOS Fibrous mesothelioma, malignant Granulocytic sarcoma Fibrous mesothelioma, NOS Granulosa cell carcinoma Fibroxanthoma, malignant Granulosa cell tumor, malignant Follicular adenocarcinoma, moderately differentiated Granulosa cell tumor, sarcomatoid Follicular adenocarcinoma, NOS Grawitz tumor [obs] Follicular adenocarcinoma, trabecular Guglielmo disease Follicular adenocarcinoma, well differentiated Follicular carcinoma, encapsulated -H-Follicular carcinoma, minimally invasive Follicular carcinoma, moderately differentiated Hairy cell leukemia Follicular carcinoma, NOS Hairy cell leukemia variant Follicular carcinoma, oxyphilic cell Heavy chain disease, NOS Follicular carcinoma, trabecular Hemangioendothelial sarcoma Follicular carcinoma, well differentiated Hemangioendothelioma, malignant Hemangiopericytoma, malignant Follicular dendritic cell sarcoma Hemangiosarcoma Follicular dendritic cell tumor Hepatoblastoma Franklin disease Hepatocarcinoma Hepatocellular carcinoma, clear cell type -G-Hepatocellular carcinoma, fibrolamellar G cell tumor, malignant Hepatocellular carcinoma, NOS Gamma heavy chain disease Hepatocellular carcinoma, pleomorphic type Ganglioglioma, anaplastic Hepatocellular carcinoma, sarcomatoid Ganglioneuroblastoma Hepatocellular carcinoma, scirrhous Gastrin cell tumor, malignant Hepatocellular carcinoma, spindle cell variant Gastrinoma, malignant Hepatocholangiocarcinoma Gastrointestinal stromal sarcoma Hepatoid adenocarcinoma Gastrointestinal stromal tumor, malignant Hepatoid carcinoma Gelatinous adenocarcinoma [obs] Hepatoid yolk sac tumor Gelatinous carcinoma [obs] Hepatoma, malignant Gemistocytic astrocytoma Hepatoma, NOS

Gemistocytoma

Hepatosplenic (gamma-delta) lymphoma

Appendix B Reportable List

Hidradenocarcinoma Infiltrating duct and lobular carcinoma in situ High grade surface osteosarcoma Infiltrating duct and mucinous carcinoma Histiocyte-rich large B-cell lymphoma Infiltrating duct and tubular carcinoma Histiocytic medullary reticulosis [obs] Infiltrating duct carcinoma, NOS Histiocytic sarcoma Infiltrating duct mixed with other types of carcinoma Hodgkin disease, lymphocyte depletion, diffuse fibrosis Infiltrating ductular carcinoma Hodgkin disease, lymphocyte depletion, NOS Infiltrating lobular carcinoma Hodgkin disease, lymphocyte depletion, reticular Infiltrating lobular carcinoma and ductal carcinoma in situ Hodgkin disease, lymphocyte predominance, diffuse Infiltrating lobular mixed with other types of carcinoma Infiltrating papillary adenocarcinoma [obs] Hodgkin disease, lymphocyte predominance, nodular Inflammatory adenocarcinoma Hodgkin disease, lymphocyte predominance, NOS [obs] Inflammatory carcinoma Hodgkin disease, lymphocytic-histiocytic predominance Inflammatory liposarcoma Insular carcinoma [obs] Hodgkin disease, mixed cellularity, NOS Insulinoma, malignant Hodgkin disease, nodular sclerosis, cellular phase Interdigitating cell sarcoma Hodgkin disease, nodular sclerosis, lymphocyte Interdigitating dendritic cell sarcoma Interstitial cell tumor, malignant depletion Hodgkin disease, nodular sclerosis, lymphocyte Intestinal T-cell lymphoma predominance Intracortical osteosarcoma Intracystic carcinoma, NOS Hodgkin disease, nodular sclerosis, mixed cellularity Hodgkin disease, nodular sclerosis, NOS Intracystic papillary adenocarcinoma Hodgkin disease, nodular sclerosis, syncytial variant Intraductal adenocarcinoma, noninfiltrating, NOS Hodgkin disease, NOS Intraductal and lobular carcinoma Hodgkin granuloma [obs] Intraductal carcinoma and lobular carcinoma in situ Hodgkin lymphoma, lymphocyte depletion, diffuse Intraductal carcinoma, clinging Intraductal carcinoma, noninfiltrating, NOS fibrosis Hodgkin lymphoma, lymphocyte depletion, NOS Intraductal carcinoma, NOS Hodgkin lymphoma, lymphocyte depletion, reticular Intraductal carcinoma, solid type Hodgkin lymphoma, lymphocyte predominance, nodular Intraductal micropapillary carcinoma Hodgkin lymphoma, lymphocyte-rich Intraductal papillary adenocarcinoma, NOS Hodgkin lymphoma, mixed cellularity, NOS Intraductal papillary adenocarcinoma with invasion Hodgkin lymphoma, nodular lymphocyte predominance Intraductal papillary carcinoma, NOS Hodgkin lymphoma, nodular sclerosis, cellular phase Intraductal papillary-mucinous carcinoma, invasive Hodgkin lymphoma, nodular sclerosis, grade 1 Intraductal papillary-mucinous carcinoma, non-invasive Hodgkin lymphoma, nodular sclerosis, grade 2 Intraepidermal carcinoma, NOS Intraepithelial carcinoma, NOS Hodgkin lymphoma, nodular sclerosis, NOS Hodgkin lymphoma, NOS Intraepithelial neoplasia, grade III, of vulva or vagina Hodgkin paragranuloma, nodular [obs] Intraepithelial squamous cell carcinoma Hodgkin paragranuloma, NOS [obs] Intraosseous carcinoma Hodakin sarcoma [obs] Intraosseous low grade osteosarcoma Hurthle cell adenocarcinoma Intraosseous well differentiated osteosarcoma Hurthle cell carcinoma Intratubular germ cell neoplasia Intratubular malignant germ cells Hutchinson melanotic freckle, NOS Hypereosinophilic syndrome Intravascular B-cell lymphoma Intravascular bronchial alveolar tumor [obs] Hypernephroma [obs] Intravascular large B-cell lymphoma Islet cell adenocarcinoma Islet cell carcinoma Idiopathic hemorrhagic thrombocythemia Idiopathic thrombocythemia -J-Immature teratoma, malignant Immature teratoma, NOS Juvenile astrocytoma (reportable as behavior 3 in North Immunoblastic sarcoma [obs] America) Immunocytoma [obs] Juvenile carcinoma of breast Immunoproliferative disease, NOS Juvenile chronic myelomonocytic leukemia Immunoproliferative small intestinal disease Juvenile myelomonocytic leukemia Infantile fibrosarcoma Juxtacortical chondrosarcoma Infiltrating and papillary adenocarcinoma Juxtacortical osteogenic sarcoma [obs] (see Infiltrating duct adenocarcinoma Juxtacortical osteosarcoma) Infiltrating duct and colloid carcinoma Juxtacortical osteosarcoma

Infiltrating duct and cribriform carcinoma Infiltrating duct and lobular carcinoma

-K-

Reportable List Appendix B

Kaposi sarcoma Klatskin tumor Krukenberg tumor (/6) Kupffer cell sarcoma -L-Langerhans cell histiocytosis, disseminated Langerhans cell histiocytosis, generalized Langerhans cell sarcoma

Large cell (Ki-1+) lymphoma [obs]

Large cell carcinoma, NOS

Large cell carcinoma with rhabdoid phenotype

Large cell medulloblastoma

Large cell neuroendocrine carcinoma

LCIS, NOS

Leiomyosarcoma, NOS Lennert lymphoma Lentigo maligna

Lentigo maligna melanoma Leptomeningeal sarcoma

Letterer-Siwe disease

Leukemia, NOS

Leukemic reticuloendotheliosis

Leydig cell tumor, malignant

Linitis plastica Lipid-rich carcinoma Lipoma-like liposarcoma

Liposarcoma, differentiated

Liposarcoma, NOS

Liposarcoma, well differentiated

Liver cell carcinoma Lobular adenocarcinoma Lobular and ductal carcinoma Lobular carcinoma in situ, NOS

Lobular carcinoma, noninfiltrating

Lobular carcinoma, NOS

Lymphangioendothelioma, malignant

Lymphangioendothelial sarcoma

Lymphangiosarcoma

Lymphatic leukemia, NOS [obs] Lymphoblastic leukemia, L1 type

Lymphoblastic leukemia, L2 type

Lymphoblastic leukemia, NOS

Lymphoblastoma [obs]

Lymphocytic leukemia, NOS [obs]

Lymphoepithelial carcinoma

Lymphoepithelioid lymphoma

Lymphoepithelioma

Lymphoepithelioma-like carcinoma

Lymphoid leukemia, NOS

Lymphoma, NOS

Lymphomatoid papulosis

Lymphosarcoma cell leukemia [obs] Lymphosarcoma, diffuse [obs]

Lymphosarcoma, NOS [obs]

#### -M-

M<sub>6</sub>A M<sub>6</sub>B

Malignancy

Malignant chondroid syringoma

Malignant cystic nephroma

Malignant eccrine spiradenoma

Malignant fibrous histiocytoma

Malignant giant cell tumor of soft parts

Malignant histiocytosis

Malignant lymphoma, centroblastic, diffuse Malignant lymphoma, centroblastic, follicular

Malignant lymphoma, centroblastic, NOS

Malignant lymphoma, centroblastic-centrocytic, diffuse [obs]

Malignant lymphoma, centroblastic-centrocytic, follicular [obs]

Malignant lymphoma, centroblastic-centrocytic NOS [obs]

Malignant lymphoma, centrocytic [obs]

Malignant lymphoma, cleaved cell, NOS [obs]

Malignant lymphoma, convoluted cell [obs]

Malignant lymphoma, diffuse, NOS

Malignant lymphoma, follicle center, follicular

Malignant lymphoma, follicle center, NOS

Malignant lymphoma, follicular, grade 1

Malignant lymphoma, follicular, grade 2

Malignant lymphoma, follicular, grade 3

Malignant lymphoma, follicular, NOS

Malignant lymphoma, histiocytic, diffuse

Malignant lymphoma, histiocytic, nodular [obs] Malignant lymphoma, histiocytic, NOS [obs]

Malignant lymphoma, Hodgkin

Malignant lymphoma, immunoblastic, NOS

Malignant lymphoma, large B-cell, diffuse, centroblastic, NOS

Malignant lymphoma, large B-cell, diffuse,

immunoblastic, NOS

Malignant lymphoma, large B-cell, diffuse, NOS

Malignant lymphoma, large B-cell, NOS

Malignant lymphoma, large cell, cleaved and noncleaved

Malignant lymphoma, large cell, cleaved, diffuse

Malignant lymphoma, large cell, cleaved, NOS [obs]

Malignant lymphoma, large cell, diffuse, NOS [obs]

Malignant lymphoma, large cell, follicular, NOS

Malignant lymphoma, large cell, immunoblastic

Malignant lymphoma, large cell, noncleaved, diffuse,

NOS [obs]

Malignant lymphoma, large cell, noncleaved, NOS Malignant lymphoma, large cell, noncleaved, follicular

Malignant lymphoma, large cell, noncleaved, NOS

Malignant lymphoma, large cell, NOS

Malignant lymphoma, large cleaved cell, follicular [obs]

Malignant lymphoma, large cleaved cell, NOS [obs]

Malignant lymphoma, lymphoblastic, NOS

Malignant lymphoma, lymphocytic, diffuse, NOS

Malignant lymphoma, lymphocytic, intermediate

differentiation, diffuse [obs]

Malignant lymphoma, lymphocytic, intermediate differentiation, nodular [obs]

Malignant lymphoma, lymphocytic, nodular, NOS [obs]

Malignant lymphoma, lymphocytic, NOS

Malignant lymphoma, lymphocytic, poorly differentiated, diffuse [obs]

Appendix B Reportable List

Malignant lymphoma, lymphocytic, poorly differentiated, nodular [obs]

Malignant lymphoma, lymphocytic, well differentiated, diffuse

Malignant lymphoma, lymphocytic, well differentiated, nodular [obs]

Malignant lymphoma, lymphoplasmacytic

Malignant lymphoma, lymphoplasmacytoid

Malignant lymphoma, mixed cell type, diffuse [obs] Malignant lymphoma, mixed cell type, follicular [obs] Malignant lymphoma, mixed cell type, nodular [obs] Malignant lymphoma, mixed lymphocytic-histiocytic, diffuse [obs]

Malignant lymphoma, mixed lymphocytic-histiocytic, nodular [obs]

Malignant lymphoma, mixed small and large cell, diffuse [obs]

Malignant lymphoma, mixed small cleaved and large cell, follicular [obs]

Malignant lymphoma, nodular, NOS [obs] Malignant lymphoma, non-Hodgkin, NOS

Malignant lymphoma, non-cleaved, diffuse, NOS [obs] Malignant lymphoma, non-cleaved, follicular, NOS [obs]

Malignant lymphoma, non-cleaved, NOS Malignant lymphoma, non-cleaved cell, NOS

Malignant lymphoma, NOS

Malignant lymphoma, plasmacytoid [obs]

Malignant lymphoma, small B lymphocytic, NOS

Malignant lymphoma, small cell diffuse

Malignant lymphoma, small cell, noncleaved, diffuse [obs]

Malignant lymphoma, small cell, NOS

Malignant lymphoma, small cleaved cell, diffuse [obs] Malignant lymphoma, small cleaved cell, follicular [obs] Malignant lymphoma, small cleaved cell, NOS [obs] Malignant lymphoma, small lymphocytic, diffuse Malignant lymphoma, small lymphocytic, NOS Malignant lymphoma, small noncleaved, Burkitt type [obs]

Malignant lymphoma, undifferentiated, Burkitt type [obs] Malignant lymphoma, undifferentiated cell, non-Burkitt

Malignant lymphoma, undifferentiated cell type, NOS

Malignant lymphomatous polyposis [obs]

Malignant mast cell tumor Malignant mastocytoma Malignant mastocytosis

Malignant melanoma in congenital melanocytic nevus

Malignant melanoma in giant pigmented nevus Malignant melanoma in Hutchinson melanotic freckle

Malignant melanoma in junctional nevus

Malignant melanoma in precancerous melanosis

Malignant melanoma, NOS Malignant melanoma, regressing Malignant midline reticulosis [obs] Malignant mucinous adenofibroma Malignant mucinous cystadenofibroma Malignant multilocular cystic nephroma Malignant myelosclerosis [obs] Malignant myoepithelioma

Malignant peripheral nerve sheath tumor

Malignant peripheral nerve sheath tumor with rhabdomyoblastic differentiation

Malignant reticulosis, NOS [obs]

Malignant rhabdoid tumor

Malignant Schwannoma, NOS [obs]

Malignant Schwannoma with rhabdomyoblastic differentiation

Malignant serous adenofibroma Malignant serous cystadenofibroma Malignant tenosynovial giant cell tumor

Malignant teratoma, anaplastic Malignant teratoma, intermediate Malignant teratoma, trophoblastic Malignant teratoma, undifferentiated Malignant tumor, clear cell type

Malignant tumor, fusiform cell type Malignant tumor, giant cell type Malignant tumor, small cell type

Malignant tumor, spindle cell type MALT lymphoma

Mantle cell lymphoma Mantle zone lymphoma [obs]

Marginal zone B-cell lymphoma, NOS

Marginal zone lymphoma, NOS

Mast cell leukemia Mast cell sarcoma Mature T ALL

Mature T-cell lymphoma, NOS Mediastinal large B-cell lymphoma

Mediterranean lymphoma Medullary adenocarcinoma Medullary carcinoma, NOS

Medullary carcinoma with amyloid stroma Medullary carcinoma with lymphoid stroma

Medullary osteosarcoma Medulloblastoma, NOS Medulloepithelioma, NOS Medullomyoblastoma

Megakaryoblastic leukemia, NOS

Megakaryocytic leukemia Megakaryocytic myelosclerosis

Melanoma in situ

Melanoma, malignant, of soft parts

Melanoma, NOS

Melanotic medulloblastoma

Melanotic MPNST

Melanotic psammomatous MPNST

Meningeal melanomatosis Meningeal sarcoma Meningeal sarcomatosis Meningioma, anaplastic Meningioma, malignant Meningothelial sarcoma Merkel cell carcinoma Merkel cell tumor

Mesenchymal chondrosarcoma Mesenchymal tumor, malignant Mesenchymoma, malignant Mesodermal mixed tumor Mesonephric adenocarcinoma Mesonephroma, malignant Mesonephroma, NOS

Reportable List Appendix B

Mesothelioma, biphasic, malignant Mesothelioma, biphasic, NOS Mesothelioma, malignant Mesothelioma, NOS

Metaplastic carcinoma, NOS Microcystic adnexal carcinoma

Microglioma [obs]

Micropapillary serous carcinoma Mixed acidophil-basophil carcinoma Mixed acinar-endocrine carcinoma

Mixed adenocarcinoma and epidermoid carcinoma Mixed adenocarcinoma and squamous cell carcinoma

Mixed carcinoid-adenocarcinoma Mixed cell adenocarcinoma

Mixed ductal-endocrine carcinoma

Mixed embryonal carcinoma and teratoma

Mixed embryonal rhabdomyosarcoma and alveolar

rhabdomyosarcoma

Mixed epithelioid and spindle cell melanoma

Mixed germ cell tumor

Mixed glioma

Mixed hepatocellular and bile duct carcinoma Mixed islet cell and exocrine adenocarcinoma

Mixed liposarcoma

Mixed medullary-follicular carcinoma Mixed medullary-papillary carcinoma Mixed mesenchymal sarcoma

Mixed oligoastrocytoma (see Oligoastrocytoma)

Mixed pineal tumor

Mixed pineocytoma-pineoblastoma

Mixed small cell carcinoma Mixed teratoma and seminoma Mixed tumor, malignant, NOS

Mixed tumor, salivary gland type, malignant

Mixed type rhabdomyosarcoma Monoblastic leukemia, NOS Monocytic leukemia, NOS Monocytoid B-cell lymphoma Monstrocellular sarcoma [obs] MPNST with glandular differentiation
MPNST with mesenchymal differentiation

MPNST with rhabdomyoblastic differentiation MPNST, NOS

Mu heavy chain disease

Mucin-producing adenocarcinoma Mucin-producing carcinoma Mucin-secreting adenocarcinoma Mucin-secreting carcinoma

Mucinous adenocarcinofibroma

Mucinous adenocarcinoma

Mucinous adenocarcinoma, endocervical type

Mucinous carcinoid Mucinous carcinoma

Mucinous cystadenocarcinofibroma

Mucinous cystadenocarcinoma, non-invasive

Mucinous cystadenocarcinoma, NOS

Mucinous cystadenoma, borderline malignancy Mucinous cystic tumor of borderline malignancy Mucinous tumor, NOS, of low malignant potential

Mucocarcinoid tumor Mucoepidermoid carcinoma Mucoid adenocarcinoma

Mucoid carcinoma

Mucoid cell adenocarcinoma

Mucosal-associated lymphoid tissue (MALT) lymphoma

Mucosal lentiginous melanoma Mucous adenocarcinoma Mucous carcinoma

Mullerian mixed tumor

Multiple hemorrhagic sarcoma

Multiple myeloma Mycosis fungoides Myelocytic leukemia, NOS

Myelodysplastic syndrome, NOS

Myelodysplastic syndrome with 5q deletion (5q-)

syndrome

Myelofibrosis as a result of myeloproliferative disease

Myelofibrosis with myeloid metaplasia

Myelogenous leukemia, NOS Myeloid leukemia, NOS

Myeloid sarcoma Myeloma, NOS Myelomatosis

Myelomonocytic leukemia, NOS

Myelosclerosis with myeloid metaplasia

Myoepithelial carcinoma

Myosarcoma

Myxoid chondrosarcoma Myxoid leiomyosarcoma Myxoid liposarcoma Myxoliposarcoma Myxosarcoma

# -N-

Neoplasm, malignant Nephroblastoma, NOS Nephroma, NOS

Neurilemmoma, malignant [obs] Neurilemmosarcoma [obs] Neuroblastoma, NOS

Neuroectodermal tumor, NOS Neuroendocrine carcinoma, NOS

Neuroepithelioma, NOS Neurofibrosarcoma [obs] Neurogenic sarcoma [obs] Neurosarcoma [obs]

Neurotropic melanoma, malignant

NK/T-cell lymphoma, nasal and nasal-type

Nodal marginal zone lymphoma Nodular hidradenoma, malignant

Nodular melanoma

Non-Hodgkin lymphoma, NOS

Nonchromaffin paraganglioma, malignant Nonencapsulated sclerosing adenocarcinoma Nonencapsulated sclerosing carcinoma Nonencapsulated sclerosing tumor

Noninfiltrating intracystic carcinoma

Noninfiltrating intraductal papillary adenocarcinoma

Noninfiltrating intraductal papillary carcinoma

Nonlipid reticuloendotheliosis [obs] Non-lymphocytic leukemia, NOS

Non-small cell carcinoma

Appendix B Reportable List

Oat cell carcinoma
Odontogenic carcinoma
Odontogenic carcinosarcoma
Odontogenic fibrosarcoma
Odontogenic sarcoma

Odontogenic tumor, malignant

Olfactory neuroblastoma
Olfactory neuroepithelioma
Olfactory neurogenic tumor
Olfactory neurocytoma

Oligopotropytoma

Oligoastrocytoma

Oligodendroblastoma [obs]
Oligodendroglioma, anaplastic
Oligodendroglioma, NOS

Oncocytic adenocarcinoma

Oncocytic carcinoma
Orchioblastoma
Osteoblastic sarcoma

Osteochastic sarcoma
Osteoclastoma, malignant

Osteofibrosarcoma

Osteogenic sarcoma, NOS

Osteosarcoma in Paget disease of bone

Osteosarcoma, NOS Oxyphilic adenocarcinoma

# -P-

Paget disease and infiltrating duct carcinoma of breast

Paget disease and intraductal carcinoma of breast

Paget disease and initiation of Paget disease, extramammary Paget disease, mammary Paget disease of breast Pagetoid reticulosis
Pancreatoblastoma

Papillary adenocarcinoma, follicular variant

Papillary adenocarcinoma, NOS
Papillary and follicular adenocarcinoma
Papillary and follicular carcinoma
Papillary carcinoma, columnar cell
Papillary carcinoma, diffuse sclerosing
Papillary carcinoma, encapsulated
Papillary carcinoma, follicular variant

Papillary carcinoma in situ
Papillary carcinoma, NOS
Papillary carcinoma of thyroid
Papillary carcinoma, oxyphilic cell
Papillary carcinoma, tall cell

Papillary cystadenocarcinoma, NOS

Papillary cystadenoma, borderline malignancy

Papillary ependymoma
Papillary epidermoid carcinoma

Papillary meningioma
Papillary microcarcinoma

Papillary mucinous cystadenocarcinoma

Papillary mucinous cystadenoma, borderline malignancy
Papillary mucinous tumor of low malignant potential
Papillary pseudomucinous cystadenocarcinoma
Papillary pseudomucinous cystadenoma, borderline
malignancy

Papillary renal cell carcinoma
Papillary serous adenocarcinoma

Papillary serous cystadenocarcinoma

Papillary serous cystadenoma, borderline malignancy Papillary serous tumor of low malignant potential

Papillary squamous cell carcinoma

Papillary squamous cell carcinoma in situ

Papillary squamous cell carcinoma, non-invasive

Papillary transitional cell carcinoma

Papillary transitional cell carcinoma, non-invasive

Papillary urothelial carcinoma

Papillary urothelial carcinoma, non-invasive

Papillocystic adenocarcinoma
Papillotubular adenocarcinoma
Parafollicular cell carcinoma
Paraganglioma, malignant
Parietal cell adenocarcinoma

Parietal cell carcinoma
Parosteal osteosarcoma
Perineural MPNST
Perineurioma, malignant
Periosteal chondrosarcoma
Periosteal fibrosarcoma

Periosteal osteogenic sarcoma (see Periosteal

osteosarcoma)

<u>Periosteal</u> <u>osteosarcoma</u> Periosteal sarcoma, NOS

Peripheral neuroectodermal tumor

Peripheral primitive neuroectodermal tumor, NOS
Peripheral T-cell lymphoma, AILD (Angioimmunoblastic

Lymphadenopathy with Dysproteinemia) [obs]

Peripheral T-cell lymphoma, large cell

Peripheral T-cell lymphoma, pleomorphic medium and large cell

Peripheral T-cell lymphoma, NOS

Peripheral T-cell lymphoma, pleomorphic small cell

Pheochromoblastoma

Pheochromocytoma, malignant Phyllodes tumor, malignant

Pigmented dermatofibrosarcoma protuberans

Pilocytic astrocytoma (reportable as behavior 3 in North America)

Piloid astrocytoma (reportable as behavior 3 in North America)

Pineal parenchymal tumor of intermediate differentiation

Pineoblastoma Pinkus tumor

Pituitary carcinoma, NOS
Plasma cell leukemia
Plasma cell myeloma
Plasma cell tumor
Plasmablastic lymphoma
Plasmacytic leukemia
Plasmacytic lymphoma [obs]

Plasmacytoma, extramedullary (not occurring in bone)

Plasmacytoma, NOS
<u>Plasmacytoma of bone</u>
Pleomorphic carcinoma
Pleomorphic cell sarcoma
Pleomorphic liposarcoma

Pleomorphic rhabdomyosarcoma, NOS Pleomorphic rhabdomyosarcoma, adult type

Pleomorphic xanthoastrocytoma Pleuropulmonary blastoma Reportable List Appendix B

PNET, NOS Refractory anemia with excess blasts in transformation Pneumoblastoma Polar spongioblastoma Refractory anemia with ringed sideroblasts Polycythemia rubra vera Refractory anemia with sideroblasts Polycythemia vera Refractory anemia without sideroblasts Polyembryoma Refractory cytopenia with multilineage dysplasia Polygonal cell carcinoma Renal carcinoma, collecting duct type Renal cell adenocarcinoma Polymorphic reticulosis [obs] Polymorphous low grade adenocarcinoma Renal cell carcinoma, NOS Polyvesicular vitelline tumor Renal cell carcinoma, chromophobe cell Porocarcinoma Renal cell carcinoma, chromophobe type PPNET Renal cell carcinoma, sarcomatoid Renal cell carcinoma, spindle cell Pre-B ALL Precancerous melanosis, NOS Reserve cell carcinoma Precursor B-cell lymphoblastic leukemia Reticulosarcoma, diffuse [obs] Precursor B-cell lymphoblastic lymphoma Reticulosarcoma, NOS [obs] Precursor cell lymphoblastic leukemia, NOS Reticulum cell sarcoma, diffuse [obs] Precursor cell lymphoblastic leukemia, not phenotyped Reticulum cell sarcoma, NOS [obs] Retinoblastoma, differentiated Precursor cell lymphoblastic lymphoma, NOS Precursor T-cell lymphoblastic leukemia Retinoblastoma, diffuse Precursor T-cell lymphoblastic lymphoma Retinoblastoma, NOS Preleukemia [obs] Retinoblastoma, undifferentiated Preleukemic syndrome [obs] Rhabdoid meningioma Pre-pre-B ALL Rhabdoid sarcoma Pre-T ALL Rhabdoid tumor, NOS Rhabdomyosarcoma, NOS Primary cutaneous anaplastic large cell lymphoma Primary cutaneous CD30+ large T-cell lymphoma Rhabdomyosarcoma with ganglionic differentiation Primary cutaneous CD30+ T-cell lymphoproliferative Rhabdosarcoma disorder Round cell carcinoma Primary cutaneous neuroendocrine carcinoma Round cell liposarcoma Primary effusion lymphoma Round cell osteosarcoma Primary intraosseous carcinoma Round cell sarcoma Primary serous papillary carcinoma of peritoneum Primitive neuroectodermal tumor, NOS -S-Primitive polar spongioblastoma [obs] **SALT** lymphoma Pro-B ALL Sarcoma botryoides Proliferative polycythemia Sarcoma, NOS Prolymphocytic leukemia, B-cell type Sarcomatoid carcinoma Prolymphocytic leukemia, NOS Sarcomatoid mesothelioma Prolymphocytic leukemia, T-cell type Schminke tumor Pro-T ALL Schneiderian carcinoma Protoplasmic astrocytoma Scirrhous adenocarcinoma Pseudoglandular squamous cell carcinoma Scirrhous carcinoma Pseudomucinous adenocarcinoma Sclerosing liposarcoma Pseudomucinous cystadenocarcinoma, NOS Sclerosing hepatic carcinoma Pseudomucinous cystadenoma, borderline malignancy Sclerosing sweat duct carcinoma Pseudomyxoma peritonei with unknown primary site Sebaceous adenocarcinoma Pseudosarcomatous carcinoma Sebaceous carcinoma Pulmonary blastoma Secretory carcinoma of breast Seminoma, anaplastic -Q-Seminoma, NOS Seminoma with high mitotic index Queyrat erythroplasia Serotonin producing carcinoid Serous adenocarcinofibroma -R-Serous adenocarcinoma. NOS **RAEB** Serous carcinoma, NOS

Refractory anemia, NOS

Refractory anemia with excess blasts

RAEB I

RAEB II

RAEB-T

RARS

Serous cystadenocarcinofibroma

Serous cystadenocarcinoma, NOS

Serous surface papillary carcinoma

Serous cystadenoma, borderline malignancy

Serous tumor, NOS, of low malignant potential

Serous papillary cystic tumor of borderline malignancy

Appendix B Reportable List

Sertoli cell carcinoma

Sertoli-Leydig cell tumor, poorly differentiated

Sertoli-Leydig cell tumor, poorly differentiated, with

heterologous elements

Sertoli-Leydig cell tumor, sarcomatoid

SETTLE

Sezary disease

Sezary syndrome

Signet ring cell adenocarcinoma

Signet ring cell carcinoma

Skin appendage carcinoma

Skin-associated lymphoid tissue lymphoma

Small cell carcinoma, fusiform cell

Small cell carcinoma, intermediate cell

Small cell carcinoma, NOS

Small cell osteosarcoma

Small cell sarcoma

Small cell-large cell carcinoma

Small cell neuroendocrine carcinoma

Soft tissue sarcoma

Soft tissue tumor, malignant

Solid adenocarcinoma with mucin formation

Solid carcinoma, NOS

Solid carcinoma with mucin formation

Solid pseudopapillary carcinoma

Solitary fibrous tumor, malignant

Solitary myeloma

Solitary plasmacytoma

Somatostatin cell tumor, malignant

Somatostatinoma, malignant

Spermatocytic seminoma

Spermatocytoma

Spindle cell carcinoma

Spindle cell melanoma, NOS

Spindle cell melanoma, type A

Spindle cell melanoma, type B

Spindle cell rhabdomyosarcoma

Spindle cell sarcoma

Spindle epithelial tumor with thymus-like differentiation

Spindle epithelial tumor with thymus-like element

Spindled mesothelioma

Splenic lymphoma with villous lymphocytes

Splenic marginal zone B-cell lymphoma

Splenic marginal zone lymphoma, NOS

Spongioblastoma multiforme

Spongioblastoma, NOS [obs]

Spongioblastoma polare

Spongioneuroblastoma

Squamous carcinoma

Squamous cell carcinoma, acantholytic

Squamous cell carcinoma, adenoid

Squamous cell carcinoma, clear cell type

Squamous cell carcinoma in situ, NOS

Squamous cell carcinoma in situ with questionable

stromal invasion

Squamous cell carcinoma, keratinizing, NOS

Squamous cell carcinoma, large cell, keratinizing

Squamous cell carcinoma, large cell, nonkeratinizing,

NOS

Squamous cell carcinoma, microinvasive

Squamous cell carcinoma, nonkeratinizing, NOS

Squamous cell carcinoma, NOS

Squamous cell carcinoma, pseudoglandular

Squamous cell carcinoma, sarcomatoid

Squamous cell carcinoma, small cell, nonkeratinizing

Squamous cell carcinoma, spindle cell

Squamous cell carcinoma with horn formation

Squamous cell epithelioma

Squamous intraepithelial neoplasia, grade III

Stem cell leukemia

Steroid cell tumor, malignant

Stromal endometriosis

Stromal myosis, NOS

Stromal sarcoma, NOS

Struma ovarii, malignant

Subacute granulocytic leukemia [obs]

Subacute leukemia, NOS [obs]

Subacute lymphatic leukemia [obs]

Subacute lymphocytic leukemia [obs]

Subacute lymphoid leukemia [obs]

Subacute monocytic leukemia [obs]

Subacute myelogenous leukemia [obs]

Subacute myelogenous leukemia <u>lob</u>

Subacute myeloid leukemia [obs]

Subcutaneous panniculitic, T-cell lymphoma (See subcutaneous panniculitis-like T-cell lymphoma)

Subcutaneous panniculitis-like T-cell lymphoma

Superficial spreading adenocarcinoma

Superficial spreading melanoma

Supratentorial PNET

Sweat gland adenocarcinoma

Sweat gland carcinoma

Sweat gland tumor, malignant

Sympathicoblastoma

Synovial sarcoma, biphasic

Synovial sarcoma, epithelioid cell

Synovial sarcoma, monophasic fibrous

Synovial sarcoma, NOS

Synovial sarcoma, spindle cell

Synovioma, malignant

Synovioma, NOS

Syringomatous carcinoma

Systemic tissue mast cell disease

# -T-

T/NK-cell lymphoma

Tanycytic ependymoma

T-cell lymphoma, NOS

T-cell rich B-cell lymphoma

T-cell rich large B-cell lymphoma

T-cell rich/histiocyte-rich large B-cell lymphoma

T-zone lymphoma

Telangiectatic osteosarcoma

Teratoblastoma, malignant

Teratocarcinoma

Teratoid medulloepithelioma

Teratoma, malignant, NOS

Teratoma with malignant transformation

Terminal duct adenocarcinoma

Thecoma, malignant

Therapy-related acute myeloid leukemia and

myelodysplastic syndrome, NOS

Therapy-related acute myeloid leukemia, alkylating

agent related

Reportable List Appendix B

Therapy-related acute myeloid leukemia,

epipodophyllotoxin-related

Therapy-related acute myeloid leukemia, NOS

<u>Therapy-related</u> <u>myelodysplastic</u> <u>syndrome</u>, <u>alkylating</u> agent related

Therapy-related myelodysplastic syndrome,

epipodophyllotoxin-related

Therapy-related myelodysplastic syndrome, NOS

Thymic carcinoma, NOS

Thymic large B-cell lymphoma

Thymoma, atypical, malignant

Thymoma, cortical, malignant

Thymoma, epithelial, malignant

Thymoma, lymphocyte-rich, malignant

Thymoma, lymphocytic, malignant

Thymoma, malignant

Thymoma, medullary, malignant

Thymoma, mixed type, malignant

Thymoma, organoid, malignant

Thymoma, predominantly cortical, malignant

Thymoma, spindle cell, malignant

Thymoma, type A, malignant

Thymoma, type AB, malignant

Thymoma, type B1, malignant

Thymoma, type B2, malignant

Thymoma, type B3, malignant

Thymoma, type C

Tibial adamantinoma

Trabecular adenocarcinoma

Trabecular carcinoma

Transitional carcinoma

Transitional cell carcinoma in situ

Transitional cell carcinoma, micropapillary

Transitional cell carcinoma, NOS

Transitional cell carcinoma, sarcomatoid

Transitional cell carcinoma, spindle cell

Transitional pineal tumor

Triton tumor, malignant

Trophoblastic tumor, epithelioid

True histiocytic lymphoma [obs]

Tubular adenocarcinoma

Tubular carcinoma

Tubulopapillary adenocarcinoma

Tumors cells, malignant

Tumor, malignant, NOS

Typical carcinoid

T-zone lymphoma

# -U-

Unclassified tumor, malignant Undifferentiated leukemia

Undifferentiated sarcoma

Urothelial carcinoma

Urothelial carcinoma in situ

#### -V-

Vaginal intraepithelial neoplasia, grade III

VAIN. III

Verrucous carcinoma, NOS

Verrucous epidermoid carcinoma

Verrucous squamous cell carcinoma

Villous adenocarcinoma

VIN. III

Vipoma, malignant

Vulvar intraepithelial neoplasia, grade III

# -W-

Waldenstrom macroglobulinemia

Warty carcinoma

Water-clear cell adenocarcinoma

Water-clear cell carcinoma

Well differentiated thymic carcinoma

Wilms tumor

Wolffian duct carcinoma

Wuchernde Struma Langhans [obs] (Deleted in ICD-O-3)

# -XYZ-

Yolk sac tumor

Appendix B Reportable List

# B. REPORTABLE BENIGN AND BORDERLINE INTRACRANIAL AND CENTRAL NERVOUS SYSTEM TUMORS

# -A-

Acidophil adenoma
Acoustic neuroma
Adamantinomatous craniopharyngioma
Adenoma, NOS
Adult cystic teratoma
Adult teratoma, NOS
Ancient schwannoma
Angioblastoma

Angioblastoma Angioendothelioma Angiolipoma, NOS Angioma, NOS

Angiomatous meningioma Atypical choroid plexus papilloma

Atypical lipoma Atypical meningioma

#### -B-

Basophil adenoma

#### -C-

Capillary hemangioma
Cavernous hemangioma
Cellular schwannoma
Central neurocytoma
Cerebellar liponeurocytoma
Chordoid glioma
Chordoid glioma of third ventricle
Chordoid meningioma
Choroid plexus papilloma, NOS
Chromophobe adenoma
Clear cell adenoma
Clear cell meningioma
Clear cell tumor, NOS
Craniopharyngioma
Cystic teratoma, NOS

# -D-

Dermoid cyst, NOS
Dermoid, NOS
Desmoplastic infantile astrocytoma
Desmoplastic infantile ganglioglioma
Diffuse melanocytosis
Diffuse meningiomatosis
Dysembryoplastic neuroepithelial tumor
Dysplastic gangliocytoma of cerebellum
(Lhermitte-Duclos)

Degenerated schwannoma

#### -E-

Endotheliomatous meningioma Eosinophil adenoma Epithelial tumor, benign

## -F-

Fibroblastic meningioma Fibrolipoma Fibroma, NOS Fibromyoma Fibrous meningioma

## -G-

Gangliocytoma
Ganglioglioma, NOS
Ganglioneuroma
Glandular papilloma
Gliofibroma
Glioneuroma [obs]
Granular cell myoblastoma, NOS
Granular cell tumor of the sellar region
Granular cell tumor, NOS

#### -H-

Hemangioblastoma
Hemangioendothelioma, benign
Hemangioendothelioma, NOS
Hemangioma simplex
Hemangioma, NOS
Hemangiopericytic meningioma [obs]
Hemangiopericytoma, benign
Hemangiopericytoma, NOS

#### -l-

Infantile hemangioma Intraneural perineurioma Intravascular leiomyomatosis

#### -J.

Juvenile hemangioma

Leiomyofibroma

# -K-

Kaposiform hemangioendothelioma

#### -1 -

Leiomyoma, NOS
Leiomyomatosis, NOS
Lipoleiomyoma
Lipoma, NOS
Lipomatous medulloblastoma
Localized fibrous tumor
Lymphoplasmacyte-rich meningioma

Reportable List <u>Appendix B</u>

#### -M-

Mature teratoma Medullocytoma Melanotic neurofibroma Melanotic schwannoma Meningeal melanocytoma Meningioma, NOS Meningiomatosis, NOS Meningothelial meningioma Metaplastic meningioma Microcystic meningioma Mixed acidophil-basophil adenoma Mixed cell adenoma

Mixed meningioma

Mixed subependymoma-ependymoma

Monomorphic adenoma Mucoid cell adenoma Multiple meningiomas Multiple neurofibromatosis Myxopapillary ependymoma

#### -N-

Neoplasm, benian Neoplasm, uncertain whether benign or malignant Nerve sheath myxoma Neurilemoma, NOS Neurinoma Neurinomatosis Neuroastrocytoma [obs] Neurocytoma Neurofibroma, NOS Neurofibromatosis, NOS Neurolipocytoma Neuroma, NOS

# -0-

Oncocytic adenoma Oncocytoma Oxyphilic adenoma

Neurothekeoma

Papillary adenoma, NOS Papillary craniopharyngioma Paraganglioma, NOS Perineurioma, NOS Pigmented schwannoma Pinealoma, NOS Pineocytoma Pituitary adenoma, NOS Plexiform hemangioma Plexiform leiomyoma Plexiform neurofibroma

Plexiform neuroma Plexiform schwannoma Prolactinoma Psammomatous meningioma Psammomatous schwannoma

#### -R-

Rathke pouch tumor Recklinghausen disease Rhabdomyoma, NOS

# -S-

Schwannoma, NOS Secretory meningioma Smooth muscle tumor, NOS Soft tissue perineurioma Soft tissue tumor, benign Solid teratoma Solitary fibrous tumor Subependymal astrocytoma, NOS Subependymal giant cell astrocytoma Subependymal glioma Subependymoma Superficial well differentiated liposarcoma Syncytial meningioma

# -T-

Teratoma, benign Teratoma, differentiated Teratoma, NOS Transitional meningioma Tumor cells, benign Tumor cells, uncertain whether benign or malignant

# -V-

Venous hemangioma Von Recklinghausen disease

# APPENDIX C: ICD-9-CM CODE SCREENING LISTS FOR CASEFINDING

Revised for 2006 ICD-9-CM code changes.

Certain *International Classification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM)* codes used by health information management (medical record) departments identify reportable neoplasms. Most reportable cases fall within the ranges of codes 140 to 208 and 230 to 234. A few additional codes outside those ranges also identify reportable neoplasms.

The following lists are intended to assist in casefinding activities that are performed in casefinding sources that use *ICD-9-CM* codes to codify the diagnoses.

Casefinding List 1	for Reportable Tumors
ICD-9-CM Codes	Diagnoses (in preferred ICD-O-3 terminology)
140.0 - 208.9	Malignant neoplasms
225.0 - 225.9	Benign neoplasm of brain and spinal cord
227.3 - 227.4	Benign neoplasm of pituitary gland, pineal body, and other intracranial endocrine-related structures
230.0 - 234.9	Carcinoma in situ
237.0 - 237.9	Neoplasms of uncertain behavior (borderline) of endocrine glands and nervous system
238.4	Polycythemia vera (9950/3)
238.6	Solitary plasmacytoma (9731/3)
238.6	Extramedullary plasmacytoma (9734/3)
238.71	Essential thrombocythemia (9962/3)
238.72	Low grade myelodysplastic syndrome lesions (includes 9980/3, 9982/3, 9985.3)
238.73	High grade myelodysplastic syndrome lesions (includes 9983/3)
238.74	Myelodysplastic syndome with 5q deletion (9986/3)
238.75	Myelodysplastic syndrome, unspecified (9985/3)
238.76	Myelofibrosis with myeloid metaplasia (9961/3)
238.79	Other lymphatic and hematopoietic tissues (includes 9960/3, 9961/3, 9970/1, 9931/3)
273.2	Gamma heavy chain disease (9762/3); Franklin disease (9762/3)
273.3	Waldenstrom macroglobulinemia (9761/3)
288.3	Hypereosinophilic syndrome (9964/3)
289.83	Myelofibrosis, NOS (9961/3)
795.06	Papanicolaou smear of cervix with cytologic evidence of malignancy (without histologic confirmation) (positive Pap smear)
V10.0 - V10.9	Personal history of malignancy (review these for recurrences, subsequent primaries, and/or subsequent treatment)
V58.0	Encounter or admission for radiotherapy
V58.11	Encounter for antineoplastic chemotherapy
V58.12	Encounter for antineoplastic immunotherapy
Procedures	
92.21-92.29	Therapeutic radiology and nuclear medicine

99.25

Injection or infusion of cancer chemotherapeutic substance

<u>Supplementary ICD-9-CM Codes to Screen for Cancer Cases Not Idenfified by Other Codes</u>
Note: Cases with these codes should be screened only as registry time allows. These are neoplasm-related secondary conditions for which there should also be a primary diagnosis of a reportable neoplasm.

ICD-9-CM Codes	Diagnoses
042	AIDS (review cases for AIDS-related malignancies)
210.0 - 229.9	Benign neoplasms (screen for incorrectly coded malignancies or reportable- by-agreement tumors)
235.0 - 236.9	Neoplasms of uncertain behavior (sceen for reportable-by-agreement tumors)
238.0 - 238.9	Neoplasms of uncertain behavior (sceen for reportable-by-agreement tumors)
239.0 - 239.9	Neoplasms of unspecified behavior (screen for incorrectly coded malignancies or reportable-by-agreement tumors)
273.9	Unspecified disorder of plasma protein metabolism (screen for potential 273.3 miscodes)
338.3	Neoplasm related pain (acute) (chronic) (new code)  Cancer associated pain
	Pain due to malignancy (primary) (secondary) Tumor associated pain
528.01	Mucositis due to antineoplastic therapy (new code)
790.93	Elevated prostate specific antigen (PSA)
795.8	Abnormal tumor markers (new sub-category)
	Elevated tumor associated antigens (TAA)
	Elevated tumor specific antigens (TSA)
	Excludes: elevated prostate specific antigen (PSA) (790.93)
795.81	Elevated carcinoembryonic antigen (CEA) (new code)
795.82	Elevated cancer antigen 125 (CA 125) (new code)
795.89	Other abnormal tumor markers (new code)
E879.2	Adverse effect of radiation therapy
E930.7	Adverse effect of antineoplastic therapy
E933.1	Adverse effect of immunosuppressive drugs
V07.3	Other prophylactic chemotherapy (screen carefully for miscoded malignancies)
V07.8	Other specified prophylactic measure
V66.1	Convalescence following radiotherapy
V66.2	Convalescence following chemotherapy
V67.1	Radiation therapy follow-up
V67.2	Chemotherapy follow-up
V76.0 - V76.9	Special screening for malignant neoplasm
V86.0	Estrogen receptor positive status (ER+) (new code)
V86.1	Estrogen receptor negative status (ER-) (new code)
	-

## Notes:

The State Cancer Registry will continue to collect pilocytic/juvenile astrocytoma, M-9421, as a behavior code /3, although the behavior was changed to code /1 in *ICD-O-3*. This is consistent with the SEER program guidelines.

For cases diagnosed 1/01/2001 and later, the State Cancer Registry will not collect borderline cystadenomas M-8442, 8451, 8462, 8472, 8473, of the ovaries which changed from behavior code /3 in *ICD-0-2* to /1 in *ICD-0-3*. This is also consistent with the SEER program guidelines.

The World Health Organization (WHO) diagnosis "B-cell chronic lymphocytic leukemia/small lymphocytic lymphoma" is coded as 9823/3, and cross-referenced to 9670/3, malignant lymphoma, small B lymphocytic. If this WHO term is diagnosed in blood or bone marrow, code 9823/3; if diagnosed in tissue, lymph nodes or any organ in combination with blood or bone marrow, code 9670/3.

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# APPENDIX D-1: ALPHABETICAL LIST OF FACILITIES WITH IDENTIFICATION NUMBERS

	Indiana	
Facility Name	ID Number	ID Number
Adams County Memorial Hospital (Decatur)	001	6420240
Ball Memorial Hospital (Muncie)		
Ball Memorial Hospital Pathology Laboratory (Muncie)	301	
Bedford Regional Medical Center (Bedford)	005	6424005
Blackford County Hospital (Hartford City)		
Bloomington Hospital and Healthcare System (Bloomington)		
Bloomington Hospital of Orange County, Inc. (Paoli)	075	6421108
Bluffton Regional Medical Center (formerly Caylor-Nickel Medical Center) (Bluffton)	009	6420140
Calumet Surgery Center (Calumet)		
Cameron Memorial Community Hospital (Angola)		
Clarian Health Partners - See Indiana University or Methodist Hospital, Indian		
Clark Memorial Hospital (Jeffersonville)	010	6420750
Columbus Regional Hospital (Columbus)		
Community Hospital (Munster)		
Community Hospital Anderson (Anderson)		
Community Hospital East (Indianapolis)		
Community Hospital North (Indianapolis)		
Community Hospital of Bremen (Bremen)		
Community Hospital South (Indianapolis)		
Community Regional Cancer Care North Pavilion (Indianapolis)		
Daviess Community Hospital (Washington)	020	6421460
Deaconess Hospital, Inc. (Evansville)		
Dearborn County Hospital (Lawrenceburg)		
Decatur County Memorial Hospital (Greensburg)		
DeKalb Memorial Hospital (Auburn)		
Dermatopathology Laboratory (Indianapolis)		
Dukes Memorial Hospital (Peru)		
Dunn Memorial Hospital (Bedford)		
Dupont Hospital (Fort Wayne)	132	10000266
Elkhart General Hospital (Elkhart)		
Evansville Cancer Center (Evansville)		
Fayette Memorial Hospital Association, Inc. (Connersville)		
Floyd Memorial Hospital & Health Services (New Albany)		
Floyd Memorial Hospital Pathology Laboratory (New Albany)		
Gibson General Hospital (Princeton)		
Good Samaritan Hospital (Vincennes)		
Goshen General Hospital (Goshen)	033	6420505
Goshen Hospital Pathology Laboratory (Goshen)		
Greater Lafayette Health Service - See Home Hospital and St. Elizabeth Med	ical Center	
Greene County General Hospital (Linton)	035	6420870
Hancock Memorial Hospital & Health Services (Greenfield)	036	6420525
Harrison County Hospital (Corydon)		
Hendricks Regional Health (Danville)		
Henry County Memorial Hospital (New Castle)		
Home Hospital (Lafayette)		
Howard Regional Health System (Kokomo)		
Indiana Surgery Center East (Indianapolis)		
Indiana Surgery Center North (Indianapolis)		
Indiana Surgery Center South (Indianapolis)		
Indiana University Hospital of Clarian Health Partners, Inc. (Indianapolis)		
Jasper County Hospital (Rensselaer)		

lov County Hoomital (Doubland)	040	0404400
Jay County Hospital (Portland)		
Johnson Memorial Hospital (Franklin)		
Kindred Hospital (Indianapolis)		
King's Daughters' Hospital and Health Services (Madison)		
Kosciusko Community Hospital (Warsaw)	055	6421440
LaGrange Community Hospital (LaGrange)		
Lakeshore Health System, St. Mary's (Gary)		
LaPorte Regional Health System (LaPorte)		
Logansport Regional Cancer Center (Logansport)		
Lutheran Hospital of Indiana, Inc. (Fort Wayne)		
Lutheran Hospital Pathology Laboratory (Fort Wayne)		
Madison County Cancer Care Center (Anderson)	808	
Major Hospital (Shelbyville)		
Margaret Mary Community Hospital (Batesville)	060	6420100
Marion General Hospital (Marion)		
Medical Center of Southern Indiana (Charlestown)	074	6421272
Memorial Hospital (Logansport)	065	6420880
Memorial Hospital and Health Care Center (Jasper)	064	6420740
Memorial Hospital of Michigan City (Michigan City)		
- merged under St. Anthony Memorial Health Center (089) 1/1/98	066	6420970
Memorial Hospital of South Bend (South Bend)	067	6421290
Methodist Hospital of Clarian Health Partners, Inc. (Indianapolis)	071	6420660
Methodist Hospital Pathology Laboratory (Indianapolis)		
Methodist Hospitals – Northlake Campus (Gary)		
Methodist Hospitals – Southlake Campus (formerly 070) (Merrillville)	069	10000267
Michiana Cancer Treatment Center (Michigan City)	209	
Morgan Hospital & Medical Center (Martinsville)		
NIMLS Outpatient Laboratory (Michigan City)		
Northwest Family Hospital (Gary) – closed 11/22/95		
Parkview Hospital (Fort Wayne)		
Parkview Hospital Pathology Laboratory (Ft. Wayne)		
Parkview Huntington Hospital (Huntington)		
Parkview Noble Hospital (formerly McCray Hospital) (Kendallville)	063	6420760
Parkview Whitley Hospital (Columbia City)		
Perry County Memorial Hospital (Tell City)		
Physician (any)		
Porter Memorial Hospital (Valparaiso)		
Pulaski Memorial Hospital (Winamac)		
Putnam County Hospital (Greencastle)		
Raymond Street Pathology Laboratory (Indianapolis)		
Reid Hospital and Health Care Services (Richmond)		
Richard L. Roudebush VA Medical Center (Indianapolis)		
River View Surgery Center (Marion)		
Riverview Hospital (Noblesville)		
Rush Memorial Hospital (Rushville)		
Schneck Medical Center (Seymour)		
Scott Memorial Hospital (Scottsburg)		
St. Anthony Medical Center (Crown Point)		
St. Anthony Memorial Health Centers (Michigan City)		
St. Catherine Hospital (East Chicago)		
St. Clare Medical Center (formerly Culver Union Hospital) (Crawfordsville)		
St. Elizabeth Ann Seton Hospital of Central Indiana (Carmel)		
St. Elizabeth Medical Center (Lafayette)		
St. Francis Hospital and Health Centers (Beech Grove)		
St. Francis Hospital – Mooresville (formerly Kendrick Memorial Hospital 052) (Mooresville)		
St. John's Health System – Cancer Center (Anderson)	094	6420050

St. Joseph Hospital (Fort Wayne)	.097	6420450
St. Joseph Hospital and Health Center (Kokomo)	.095	6420780
St. Joseph's Hospital (Huntingburg)		
St. Joseph Regional Medical Center, Mishawaka Campus (Mishawaka)	.096	6421020
St. Joseph Regional Medical Center, Plymouth Campus (Plymouth)	.040	6421150
St. Joseph Regional Medical Center, South Bend Campus (South Bend)	.099	6421300
St. Margaret Mercy Healthcare Centers North Campus (Hammond)		
St. Margaret Mercy Healthcare Centers South Campus (Dyer)	.076	6420560
St. Mary Medical Center (Hobart)		
St. Mary Medical Plaza (South Bend) - merged with St. Joseph Community (096) 1/1/98	.072	6429150
St. Mary's Warrick (Boonville)	.115	6420155
St. Mary's Laboratory (Gary/Hobart)		
St. Mary's Medical Center (Evansville)		
St. Mary's Welborn Campus (Evansville) - merged with St. Mary's Medical Center (103) 2000	.117	10000047
St. Vincent Carmel Hospital (Carmel)		
St. Vincent Clay County Hospital (Brazil)		
St. Vincent Frankfort Hospital (Frankfort)		
St. Vincent Hospital and Health Services (formerly 105) (Indianapolis)		
St. Vincent Jennings Hospital, Inc. (North Vernon)		
St. Vincent Mercy Hospital (Elwood)		
St. Vincent Randolph Hospital (Winchester)		
St. Vincent Williamsport Hospital (Williamsport)		
St. Vincent Women's Hospital (Indianapolis)		
Starke Memorial Hospital (Knox)		
Sullivan County Community Hospital (formerly Mary Sherman Hospital) (Sullivan)		
Terre Haute Regional Hospital (Terre Haute)	.107	6421360
Tipton County Memorial Hospital (Tipton)	801	6421370
Tri-State Prostate Cancer Center (Evansville)	.208	
Union City Memorial Hospital (Union City) - closed 9/17/93	. 109	6421380
Union Hospital, Inc. (Terre Haute)		
VA Northern Indiana Health Care System – Fort Wayne Division (Fort Wayne)		
Wabash County Hospital (Wabash)	.113	6421430
Washington County Memorial Hospital (Salem)		
Wells Community Hospital (Bluffton) - merged with Bluffton Regional Medical Center (009) 2001		
West Central Community Hospital (Clinton)		
Westview Hospital (Indianapolis)		
White County Memorial Hospital (Monticello)		
William Moores, M.D. & Dermatology, Inc.		
Winona Memorial Hospital (Indianapolis) - closed August 2004		
Wirth Regional Hospital (Oakland City)		
Wishard Health Services (Indianapolis)		
Wishard Hospital Pathology Laboratory (Indianapolis)	.307	
Witham Health Services (Lebanon)	.126	6420860
Women's Hospital (Newburg)		
Woodlawn Hospital (Rochester)	127	6421220

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# APPENDIX D-2: NUMERICAL LIST OF FACILITIES WITH IDENTIFICATION NUMBERS

	Indiana	ACoS
Facility Name	ID Number	ID Number
Adams County Memorial Hospital (Decatur)	001	6420240
VA Northern Indiana Health Care System – Fort Wayne Division (Fort Wayne)		
Ball Memorial Hospital (Muncie)	003	6421040
Columbus Regional Hospital (Columbus)		
Bedford Regional Medical Center (Bedford)	005	6424005
Blackford County Hospital (Hartford City)		
Bloomington Hospital and Healthcare System (Bloomington)		
Cameron Memorial Community Hospital (Angola)		
Bluffton Regional Medical Center (formerly Caylor-Nickel Medical Center) (Bluffton)		
Clark Memorial Hospital (Jeffersonville)		
St. Vincent Clay County Hospital (Brazil)		
St. Vincent Frankfort Hospital (Frankfort)		
St. Vincent Williamsport Hospital (Williamsport)		
Community Hospital East (Indianapolis)		
Community Hospital North (Indianapolis)		
Community Hospital of Bremen (Bremen)		
Community Hospital Anderson (Anderson)		
Community Hospital (Munster)		
St. Clare Medical Center (formerly Culver Union Hospital) (Crawfordsville)		
Daviess Community Hospital (Washington)		
DeKalb Memorial Hospital (Auburn)		
Deaconess Hospital, Inc. (Evansville)		
Dearborn County Hospital (Lawrenceburg)		
Decatur County Memorial Hospital (Greensburg)		
Dukes Memorial Hospital (Peru)		
Dunn Memorial Hospital (Bedford)		
Elkhart General Hospital (Elkhart)		
Fayette Memorial Hospital Association, Inc. (Connersville)		
Floyd Memorial Hospital & Health Services (New Albany)	029	6421045
Gibson General Hospital (Princeton)		
Good Samaritan Hospital (Vincennes)		
Goshen General Hospital (Goshen)		
Greene County General Hospital (Linton)		
Hancock Memorial Hospital & Health Services (Greenfield)		
Harrison County Hospital (Corydon)		
Hendricks Regional Health (Danville)		
Henry County Memorial Hospital (New Castle)		
St. Joseph Regional Medical Center, Plymouth Campus (Plymouth)		
Howard Regional Health System (Kokomo)		
St. Vincent Women's Hospital (Indianapolis)		
Parkview Huntington Hospital (Huntington)	043	6420590
Indiana University Hospital of Clarian Health Partners, Inc. (Indianapolis)		
Schneck Medical Center (Seymour)		
Jasper County Hospital (Rensselaer)		
Jay County Hospital (Portland)		
St. Vincent Jennings Hospital, Inc. (North Vernon)		
Johnson Memorial Hospital (Franklin)	051	0420405
King's Daughters' Hospital and Health Services (Madison)		
Kosciusko Community Hospital (Warsaw)		
LaGrange Community Hospital (LaGrange)		
LaPorte Regional Health System (LaPorte)	057	6420850

Home Hospital (Lafayette)	Homo Hoonital (Lafayatta)	OFO	10000000
Margaret Mary Community Hospital (Batesville).         .660.         .6420100           Marion General Hospital (Marion).         .061.         .6420920           Sullivan County Community Hospital (formerly Mary Sherman Hospital) (Sullivan).         .062.         .6421310           Parkview Nobie Hospital (formerly Mccray Hospital) (Kendallville).         .063.         .6420740           Memorial Hospital (Logansport).         .065.         .6420740           Memorial Hospital of Michigan City (Michigan City)         .066.         .6420790           merged under St. Anthony Memorial Heaith Center (1989) 1/1/198.         .066.         .6420970           Memorial Hospital of Sulth Bend (South Bend).         .067.         .6421290           St. Vincent Mercy Hospital (Elwood).         .068.         .6420280           Methodist Hospitals - Northlake Campus (Gary).         .069.         10000267           Methodist Hospitals - Southlake Campus (formerly 070) (Merriliville).         .069.         10000267           Methodist Hospital of Clarian Health Partners, Inc. (Indianapolis).         .071.         .6420660           Methodist Hospital & Medical Center (Martinsville).         .073.         .6429150           Medical Center of Southern Indiana (Charlestown).         .074.         .6421050           Medical Center of Southern Indiana (Charlestown).         .075. <t< td=""><td></td><td></td><td></td></t<>			
Marion General Hospital (Marion)			
Sullivan County Community Hospital (formerly Maray Sherman Hospital) (Sullivan)         .062			
Parkview Noble Hospital (formerly McCray Hospital) (Kendallville)         .063         .6420740           Memorial Hospital (Logansport)         .064         .6420740           Memorial Hospital (Logansport)         .065         .6420880           Memorial Hospital of Michigan City (Michigan City)         .065         .6420880           Memorial Hospital of Michigan City (Michigan City)         .066         .6420970           Memorial Hospital of South Bend (South Bend)         .067         .6421290           St. Vincent Mercy Hospital (Elwood)         .068         .6420280           Methodist Hospitals - Northlake Campus (formerly 070) (Merrillville)         .069         .1000267           Methodist Hospitals - Southlake Campus (formerly 070) (Merrillville)         .069         .1000267           Methodist Hospital Selection (Carlant Health Partners, Inc. (Indianapolis)         .071         .6420660           St. Mary Medical Plaza (South Bend) - merged with St. Joseph Community (086) 1/1/98         .072         .6429150           Morgan Hospital & Medical Center (Martinsville)         .073         .6420560           Medical Center of Southern Indiana (Charlestown)         .074         .6421272           Boomington Hospital (Torange County, Inc. (Paoli)         .075         .6421108           St. Margaret Mercy Healthcare Centers South Campus (Dev)         .076			
Memorial Hospital (Logansport)			
Memorial Hospital of Michigan City (Michigan City)         — merged under St. Anthony Memorial Health Center (088) 1/1/98         066         6420970           Memorial Hospital of South Bend (South Bend)         067         6421290           St. Vincent Mercy Hospital (Elwood)         068         6420280           Methodist Hospitals – Northlake Campus (Gany)         069         10000267           Methodist Hospitals – Southlake Campus (Geny)         069         10000267           Methodist Hospitals – Southlake Campus (Geny)         069         10000267           Methodist Hospitals – South Bend) – merged with St. Joseph Community (096) 1/1/98         072         6429150           Morgan Hospital & Medical Center (Martinsville).         073         642960           Medical Center of Southern Indiana (Charlestown)         074         6421272           Bloomington Hospital of Orange County, Inc. (Paoli)         075         6420560           Parkview Hospital (Fort Wayne)         077         642040           Perry County Memorial Hospital (Tell City)         078         6421325           Porter Memorial Hospital (Walparaiso)         079         6421390           Putlaski Memorial Hospital (Winchester)         082         6420520           St. Vincent Randolph Hospital (Winchester)         082         6420520           Riveriew Hospit			
Memorial Hospital of Michigan City (Michigan City)   Pereped under St. Anthony Memorial Health Center (089) 1/1/98   066   6420370   Memorial Hospital of South Bend (South Bend)   067   6421290   St. Vincent Mercy Hospital (Elwood)   068   6420280   Methodist Hospitals   Southlake Campus (Gary)   069   00000267   Methodist Hospitals   Southlake Campus (Iomerly 070) (Merrillville)   069   00000267   Methodist Hospitals   Southlake Campus (Iomerly 070) (Merrillville)   069   00000267   Methodist Hospitals   Southlake Campus (Iomerly 070) (Merrillville)   069   07000267   Methodist Hospitals   Southlake Campus (Iomerly 070) (Merrillville)   072   6429150   073   0740960   074096			
merged under St. Anthony Memorial Health Center (089) 11/198   066   6420970   Memorial Hospital of South Bend (South Bend)   067   6421290   051   052		065	6420880
Memorial Hospital of South Bend (South Bend)			
St. Vincent Mercy Hospital (Elwood)         .068         .6420280           Methodist Hospitals – Northlake Campus (Gary)         .069         .10000267           Methodist Hospitals – Southlake Campus (formerly 070) (Merrillville)         .069         .10000267           Methodist Hospital of Clarian Health Partners, Inc. (Indianapolis)         .071         .6420650           St. Mary Medical Plaza (South Bend) – merged with st. Joseph Community (1965) 1/1/98         .072         .6429150           Morgan Hospital & Medical Center (Martinsville)         .073         .6420860           Medical Center of Southern Indiana (Charlestown)         .074         .6421702           Bloomington Hospital of Orange County, Inc. (Paoli)         .075         .6421108           St. Margaret Mercy Healthcare Centers South Campus (Dyer)         .076         .6420640           Perry County Memorial Hospital (Tell City)         .078         .6421108           Putherry County Memorial Hospital (Valparaiso)         .079         .642040           Petry County Memorial Hospital (Winchester)         .082         .642185           Putham County Hospital (Greencastle)         .082         .642185           Putham County Hospital (Mobilation)         .084         .6421190           Richard L. Rudolph Hospital (Winchester)         .083         .6421485           Putham			
Methodist Hospitals – Northlake Campus (formerly 070) (Merrillville)         .069         .10000267           Methodist Hospitals – Southlake Campus (formerly 070) (Merrillville)         .069         .10000267           Methodist Hospital of Clarian Health Partners, Inc. (Indianapolis)         .071         .6420660           St. Mary Medical Plaza (South Bend) – merged with St. Joseph Community (096) 1/1/98         .072         .6429150           Morgan Hospital of Orange County, Inc. (Paoli)         .074         .6421108           Medical Center of Southern Indiana (Charlestown)         .074         .64211272           Bloomington Hospital of Orange County, Inc. (Paoli)         .075         .6420560           Methodist Hospital (Fort Wayne)         .076         .6420560           Parkview Hospital (Fort Wayne)         .077         .6420560           Parkview Hospital (Fort Wayne)         .078         .6421390           Porter Memorial Hospital (Vilnamac)         .080         .6421390           Putnam County Hospital (Winamac)         .080         .6421390           Rutnam County Hospital (Winchester)         .083         .6421490           Riveriew Hospital (Noblesville)         .085         .6421050           St. Vincent Randolph Hospital (Winchester)         .084         .6421050           Riveriew Hospital (Fort Wayne)         .			
Methodist Hospitals – Southlake Campus (formerly 070) (Merrillville)         .069         .10000267           Methodist Hospital of Clarian Health Partners, Inc. (Indianapolis)         .071         .6420660           St. Mary Medical Plaza (South Bend) – merged with St. Joseph Community (096) 1/1/98         .072         .6429150           Morgan Hospital & Medical Center (Martinsville)         .073         .6420810           Medical Center of Southern Indiana (Charlestown)         .074         .642172           Bloomington Hospital of Orange County, Inc. (Paoli)         .075         .6421108           St. Margaret Mercy Healthicare Centers South Campus (Dyer)         .076         .6420400           Parkview Hospital (Fort Wayne)         .077         .6420440           Perry County Memorial Hospital (Tell City)         .078         .6421325           Porter Memorial Hospital (Winamac)         .080         .6421485           Putnam County Hospital (Greencastle)         .082         .6420520           St. Vincent Randolph Hospital (Winchester)         .083         .6421490           River Randolph Hospital (Winchester)         .084         .6421190           Riveriew Hospital (Noblesville)         .085         .6420520           Riveriew Hospital (Rushville)         .085         .6421035           Rush Memorial Hospital (Scottsburg)	St. Vincent Mercy Hospital (Elwood)	860	6420280
Methodist Hospitals – Southlake Campus (formerly 070) (Merrillville)         .069         .10000267           Methodist Hospital of Clarian Health Partners, Inc. (Indianapolis)         .071         .6420660           St. Mary Medical Plaza (South Bend) – merged with St. Joseph Community (096) 1/1/98         .072         .6429150           Morgan Hospital & Medical Center (Martinsville)         .073         .6420810           Medical Center of Southern Indiana (Charlestown)         .074         .642172           Bloomington Hospital of Orange County, Inc. (Paoli)         .075         .6421108           St. Margaret Mercy Healthicare Centers South Campus (Dyer)         .076         .6420400           Parkview Hospital (Fort Wayne)         .077         .6420440           Perry County Memorial Hospital (Tell City)         .078         .6421325           Porter Memorial Hospital (Winamac)         .080         .6421485           Putnam County Hospital (Greencastle)         .082         .6420520           St. Vincent Randolph Hospital (Winchester)         .083         .6421490           River Randolph Hospital (Winchester)         .084         .6421190           Riveriew Hospital (Noblesville)         .085         .6420520           Riveriew Hospital (Rushville)         .085         .6421035           Rush Memorial Hospital (Scottsburg)	Methodist Hospitals – Northlake Campus (Gary)	069	10000267
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Medical Center of Southern Indiana (Charlestown)         074         6421272           Bloomington Hospital of Orange County, Inc. (Paoli)         075         6421108           St. Margaret Mercy Healthcare Centers South Campus (Dyer)         076         6420560           Parkview Hospital (Fort Wayne)         077         6420440           Perry County Memorial Hospital (Valparaiso)         079         6421325           Porter Memorial Hospital (Winamac)         080         6421485           Putnam County Hospital (Greencastle)         082         6420520           St. Vincent Randolph Hospital (Winchester)         083         6421492           Reid Hospital and Health Care Services (Richmond)         084         6421190           Riverview Hospital (Noblesville)         085         6421093           Richard L. Roudebush VA Medical Center (Indianapolis)         086         6420735           Rush Memorial Hospital (Scottsburg)         087         6421255           Scott Memorial Hospital (Scottsburg)         088         6421000           St. Anthony Medical Center (Crown Point)         090         642000           St. Catherine Hospital (Fast Chicago)         091         642000           St. Francis Hospital and Health Centers (Beech Grove)         093         10000008           St. Francis Hospital			
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Riverview Hospital (Noblesville)			
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Rush Memorial Hospital (Rushville)         087         6421255           Scott Memorial Hospital (Scottsburg)         088         6421259           St. Anthony Memorial Health Centers (Michigan City)         089         6421000           St. Anthony Medical Center (Crown Point)         090         6420225           St. Catherine Hospital (East Chicago)         091         6420260           St. Elizabeth Medical Center (Lafayette)         092         10000082           St. Francis Hospital and Health Centers (Beech Grove)         093         10000014           St. Francis Hospital – Mooresville (formerly Kendrick Memorial Hospital 052) (Mooresville)         093         10000014           St. John's Health System – Cancer Center (Anderson)         094         6420050           St. Joseph Hospital and Health Center (Kokomo)         095         6420780           St. Joseph Regional Medical Center, Mishawaka Campus (Mishawaka)         096         6421020           St. Joseph Hospital (Fort Wayne)         097         6420450           St. Joseph Regional Medical Center, South Bend Campus (South Bend)         099         6421300           St. Margaret Mercy Healthcare Centers North Campus (Hammond)         100         6420500           St. Mary Medical Center (Fobart)         102         6420500           St. Mary's Medical Center (Evansville)			
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St. Joseph Hospital and Health Center (Kokomo)			
St. Joseph Regional Medical Center, Mishawaka Campus (Mishawaka)       096       6421020         St. Joseph Hospital (Fort Wayne)       097       6420450         St. Joseph's Hospital (Huntingburg)       098       6420580         St. Joseph Regional Medical Center, South Bend Campus (South Bend)       099       6421300         St. Margaret Mercy Healthcare Centers North Campus (Hammond)       100       6420560         Northwest Family Hospital (Gary) – closed 11/22/95       101       6420500         St. Mary Medical Center (Hobart)       102       6420500         St. Mary's Medical Center (Evansville)       103       10000047         St. Vincent Carmel Hospital (Carmel)       104       10000264         St. Vincent Hospital and Health Services (formerly 105) (Indianapolis)       104       6420710         Starke Memorial Hospital (Knox)       106       6420770         Terre Haute Regional Hospital (Terre Haute)       107       6421360         Tipton County Memorial Hospital (Tipton)       108       6421370         Union City Memorial Hospital (Union City) – closed 9/17/93       109       6421380         Union Hospital, Inc. (Terre Haute)       110       6420190			
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St. Joseph Regional Medical Center, South Bend Campus (South Bend)			
St. Margaret Mercy Healthcare Centers North Campus (Hammond)       100       6420560         Northwest Family Hospital (Gary) – closed 11/22/95       101       6420500         St. Mary Medical Center (Hobart)       102       6420500         St. Mary's Medical Center (Evansville)       103       10000047         St. Vincent Carmel Hospital (Carmel)       104       104000264         St. Vincent Hospital and Health Services (formerly 105) (Indianapolis)       104       6420710         Starke Memorial Hospital (Knox)       106       6420770         Terre Haute Regional Hospital (Terre Haute)       107       6421360         Tipton County Memorial Hospital (Tipton)       108       6421370         Union City Memorial Hospital (Union City) – closed 9/17/93       109       6421380         Union Hospital, Inc. (Terre Haute)       110       6421366         West Central Community Hospital (Clinton)       112       6420190			
Northwest Family Hospital (Gary) – closed 11/22/95       101       6420500         St. Mary Medical Center (Hobart)       102       6420500         St. Mary's Medical Center (Evansville)       103       10000047         St. Vincent Carmel Hospital (Carmel)       104       10400264         St. Vincent Hospital and Health Services (formerly 105) (Indianapolis)       104       6420710         Starke Memorial Hospital (Knox)       106       6420770         Terre Haute Regional Hospital (Terre Haute)       107       6421360         Tipton County Memorial Hospital (Tipton)       108       6421370         Union City Memorial Hospital (Union City) – closed 9/17/93       109       6421380         Union Hospital, Inc. (Terre Haute)       110       6421366         West Central Community Hospital (Clinton)       112       6420190			
St. Mary Medical Center (Hobart)       102       6420500         St. Mary's Medical Center (Evansville)       103       10000047         St. Vincent Carmel Hospital (Carmel)       104       10000264         St. Vincent Hospital and Health Services (formerly 105) (Indianapolis)       104       6420710         Starke Memorial Hospital (Knox)       106       6420770         Terre Haute Regional Hospital (Terre Haute)       107       6421360         Tipton County Memorial Hospital (Tipton)       108       6421370         Union City Memorial Hospital (Union City) – closed 9/17/93       109       6421380         Union Hospital, Inc. (Terre Haute)       110       6421366         West Central Community Hospital (Clinton)       112       6420190			
St. Mary's Medical Center (Evansville)       103       10000047         St. Vincent Carmel Hospital (Carmel)       104       10000264         St. Vincent Hospital and Health Services (formerly 105) (Indianapolis)       104       6420710         Starke Memorial Hospital (Knox)       106       6420770         Terre Haute Regional Hospital (Terre Haute)       107       6421360         Tipton County Memorial Hospital (Tipton)       108       6421370         Union City Memorial Hospital (Union City) - closed 9/17/93       109       6421380         Union Hospital, Inc. (Terre Haute)       110       6421366         West Central Community Hospital (Clinton)       112       6420190			
St. Vincent Carmel Hospital (Carmel)       104       10000264         St. Vincent Hospital and Health Services (formerly 105) (Indianapolis)       104       6420710         Starke Memorial Hospital (Knox)       106       6420770         Terre Haute Regional Hospital (Terre Haute)       107       6421360         Tipton County Memorial Hospital (Tipton)       108       6421370         Union City Memorial Hospital (Union City) – closed 9/17/93       109       6421380         Union Hospital, Inc. (Terre Haute)       110       6421366         West Central Community Hospital (Clinton)       112       6420190			
St. Vincent Hospital and Health Services (formerly 105) (Indianapolis) 104 6420710 Starke Memorial Hospital (Knox) 106 6420770 Terre Haute Regional Hospital (Terre Haute) 107 6421360 Tipton County Memorial Hospital (Tipton) 108 6421370 Union City Memorial Hospital (Union City) - closed 9/17/93 109 6421380 Union Hospital, Inc. (Terre Haute) 110 6421366 West Central Community Hospital (Clinton) 112 6420190			
Starke Memorial Hospital (Knox)       106       6420770         Terre Haute Regional Hospital (Terre Haute)       107       6421360         Tipton County Memorial Hospital (Tipton)       108       6421370         Union City Memorial Hospital (Union City) – closed 9/17/93       109       6421380         Union Hospital, Inc. (Terre Haute)       110       6421366         West Central Community Hospital (Clinton)       112       6420190			
Terre Haute Regional Hospital (Terre Haute) 107 6421360 Tipton County Memorial Hospital (Tipton) 108 6421370 Union City Memorial Hospital (Union City) - closed 9/17/93 109 6421380 Union Hospital, Inc. (Terre Haute) 110 6421366 West Central Community Hospital (Clinton) 112 6420190			
Tipton County Memorial Hospital (Tipton)	Starke Memorial Hospital (Knox)	106	6420770
Union City Memorial Hospital (Union City) — closed 9/17/93			
Union Hospital, Inc. (Terre Haute)			
West Central Community Hospital (Clinton)			
West Central Community Hospital (Clinton)	Union Hospital, Inc. (Terre Haute)	110	6421366
	Wabash County Hospital (Wabash)	113	6421430

St. Mary's Warrick (Boonville)	115	6420155
Washington County Memorial Hospital (Salem)		
St. Mary's, Welborn Campus (Evansville) - merged with St. Mary's Medical Center (103) 2000		
Wells Community Hospital (Bluffton) - merged with Bluffton Regional Medical Center (009) 2001	.118	6420150
Westview Hospital (Indianapolis)		
White County Memorial Hospital (Monticello)	120	6421025
Parkview Whitley Hospital (Columbia City)	121	6420197
Major Hospital (Shelbyville)		
Winona Memorial Hospital (Indianapolis) - closed August 2004	123	6420655
Wirth Regional Hospital (Oakland City)	124	6429110
Wishard Health Services (Indianapolis)		
Witham Health Services (Lebanon)	126	6420860
Woodlawn Hospital (Rochester)		
Community Hospital South (Indianapolis)	128	6420605
Kindred Hospital (Indianapolis)	129	
St. Elizabeth Ann Seton Hospital of Central Indiana (Carmel)	130	10000263
Women's Hospital (Newburg)	131	
Dupont Hospital (Fort Wayne)	132	10000266
Community Regional Cancer Care North Pavilion (Indianapolis)	201	6420605
Evansville Cancer Center (Evansville)		
Tri-State Prostate Cancer Center (Evansville)		
Michiana Cancer Treatment Center (Michigan City)	209	
Logansport Regional Cancer Center (Logansport)	211	
NIMLS Outpatient Laboratory (Michigan City)	300	
Ball Memorial Hospital Pathology Laboratory (Muncie)	. 301	
St. Mary's Laboratory (Gary/Hobart)		
Parkview Hospital Pathology Laboratory (Ft. Wayne)		
Methodist Hospital Pathology Laboratory (Indianapolis)		
Goshen Hospital Pathology Laboratory (Goshen)	305	
Dermatopathology Laboratory (Indianapolis)	306	
Wishard Hospital Pathology Laboratory (Indianapolis)	307	
Lakeshore Health System, St. Mary's (Gary)		
Raymond Street Pathology Laboratory (Indianapolis)		
Lutheran Hospital Pathology Laboratory (Fort Wayne)	310	
Floyd Memorial Hospital Pathology Laboratory (New Albany)	11	
Calumet Surgery Center (Calumet)	507	
Indiana Surgery Center North (Indianapolis)	534	6420605
Indiana Surgery Center East (Indianapolis)	535	6420605
Indiana Surgery Center South (Indianapolis)		
River View Surgery Center (Marion)		
Physician (any)	700	
William Moores, M.D. & Dermatology, Inc.	701	
Madison County Cancer Care Center (Anderson)	808	

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# APPENDIX E: RULES FOR DETERMINING MULTIPLE PRIMARIES FOR LYMPHATIC AND HEMATOPOIETIC DISEASES

Definitions of single and subsequent primaries for hematologic malignancies based on *ICD-O-3* reportable malignancies, effective for cases diagnosed 01/01/2001 and after.

Cancer registrars are often faced with multiple pathology reports for patients with hematologic malignancies, and the diagnoses reported may require different morphology codes. This is due in part to the fact that more intensive diagnostic study may yield a more specific diagnosis, and in part to the natural histories of hematopoietic diseases, which may progress from one diagnosis into another.

The table on the following pages, provided to aid the registrar in determining single versus subsequent primaries, employs the following guidelines:

- 1. "Lymphoma" is a general term for hematopoietic solid malignancies of the lymphoid series. "Leukemia" is a general term for liquid malignancies of either the lymphoid or the myeloid series. While it is recognized that some malignancies occur predominantly (or even exclusively) in liquid or solid form, because so many malignancies can potentially arise as either leukemias or lymphomas (or both), all hematopoietic malignancies are assumed to have this potential.
- 2. Malignancies of the lymphoid series are considered to be different from those of the myeloid series. Therefore, a lymphoid malignancy arising after diagnosis of a myeloid malignancy (or myelodysplastic or myeloproliferative disorder) would be considered a subsequent primary; however, a myeloid malignancy diagnosed after a previous myeloid malignancy would not count as a subsequent primary. Histiocytic malignancies are considered different from both lymphoid and myeloid malignancies.
- 3. Hodgkin lymphoma is considered to be different from non-Hodgkin lymphoma (NHL). Among the NHLs, B-cell malignancies are considered different from T-cell/NK cell malignancies. Therefore, a B-cell malignancy arising later in the course of a patient previously diagnosed with a T-cell malignancy would be considered a subsequent primary. However, a T-cell malignancy diagnosed later in the same patient would not be considered a subsequent primary.
- 4. The sequence of diagnoses affects whether a diagnosis represents a subsequent primary. In some cases, the order of occurrence of the two diagnoses being compared is a factor in the decision as to whether the second diagnosis is a new primary.

## How to Use the Table

Assign the *ICD-O-3* code to the first diagnosis and find the row containing that code. Assign the *ICD-O-3* code for the second diagnosis and find the column containing that code. In the cell at the intersection of the first diagnosis row and the second diagnosis column, an "S" symbol indicates that the two diagnoses are most likely the **same** disease process (prepare/update a single abstract), and a "D" indicates that they are most likely **different** disease processes (prepare more than one abstract).

**Note 1:** If one of the two diagnoses is an NOS (not otherwise specified) term and the other is more specific and determined to be the same disease process, code the more specific diagnosis regardless of the sequence. For example, if a diagnosis of non-Hodgkin lymphoma, NOS is followed by a diagnosis of follicular lymphoma, assign the morphology code for the follicular lymphoma.

**Note 2:** The table (pages 294-299) and the "Complete Diagnostic Terms for Table (Based on *ICD-O-3*)" (page 300) display only the *ICD-O-3* primary (boldfaced) term associated with the code. Refer to the *International Classification of Diseases, Third Edition (ICD-O-3)* for a complete list of related terms and synonyms.

# Prepared by: SEER Program, NCI, 02/28/2001. E-mail: seerweb@ims.nci.nih.gov

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Second Diagnosis Across →  ✓ First Diagnosis Down		. <b>9590</b> Malignant lymphoma, NOS	. <b>9591</b> NHL, NOS	. <b>9596</b> Composite HD/NHL	. <b>9650-9667</b> Hodgkin lymphoma	5. <b>9670-9671</b> ML, small B lymph	. <b>9673</b> Mantle cell lymphoma	7. <b>9675-9684</b> ML, diff large B-cell	. <b>9687</b> Burkitt lymphoma	9. <b>9689,9699</b> Marg zn, B-cl lymph
Malignant lymphoma, NOS	9590	S	-S	<del>ن</del> S	8 4.	S	ý S	S	∞i S	S
Malignant lymphoma, non-Hodgkin, NOS	9590	S		 D	 D	S	S	S	S	<u>S</u>
3. Composite HD/NHL	9596	S	S	S	S	S	S	S	S	S
4. Hodgkin lymphoma	9650-9667	S	D	D	S	D	D	D	D	D
5. Malignant lymphoma, small B lymphocytic	9670-9671	S	S	D	D	S	D	S	D	D
6. Mantle cell lymphoma	9673	S	S	D	D	D	S	D	D	D
7. Malignant lymphoma, diffuse, large B-cell	9675-9684	S	S	D	D	S	D	S	S	D
8. Burkitt lymphoma	9687	S	S	D	D	D	D	D	S	D
9. Marginal zone, B-cell lymphoma	9689, 9699	S	S	D	D	D	D	D	D	S
10. Follicular lymphoma	9690-9698	S	S	D	D	D	D	<u>S</u>	D	<u>D</u>
11. Mycosis fungoides, Sezary disease 12. T/NK-cell non-Hodgkin lymphoma	9700-9701	S S	S	D D	D D	D D	D D	D D	D D	D D
13. Precursor lymphoblastic lymphoma, NOS	9702-9719 9727	S	S	D	D	D	D	D	D	D
14. Precursor B-cell lymphoblastic lymphoma	9728	S	S	D	D	D	D	D	D	
15. Precursor T-cell lymphoblastic lymphoma	9729	S	S	D	D	D	D	D	D	D
16. Plasma cell tumors	9731-9734	D	D	D	D	D	D	D	D	D
17. Mast cell tumors	9740-9742	D	D	D	D	D	D	D	D	D
18. Histiocytosis/Langerhans cell histiocytosis	9750-9756	D	D	D	D	D	D	D	D	D
19. Dendritic cell sarcoma	9757-9758	S	S	D	D	D	D	D	D	D
20. Immunoproliferative disease, NOS	9760	S	S	D	D	S	D	S	D	D
21. Waldenstrom macroglobulinemia	9761	S	S	D	D	S	D	S	D	D
22. Heavy chain disease, NOS	9762	S	S	D	D	D	D	D	D	D
23. Immunoproliferative small intestinal disease	9764	S	S	D	D	D	D	D	D	D
24. Leukemia/Acute leukemia, NOS	9800-9801	S	S	D	D	D	D	D	S	D
25. Acute biphenotypic leukemia	9805	S	S	D	D	S	S	S	S	S
26. Lymphocytic leukemia, NOS	9820 9823	S	S	D	D D	D S	D D	D S	S	D D
27. BCLL/SLL 28. Burkitt cell leukemia	9826	S	S	D D	D	 D	D	D D	D S	D
29. Adult T-cell leukemia/lymphoma	9827	S	S	D	D	D	D	D		D
30. Prolymphocytic leukemia, NOS	9832	D	D	D	D	S	D	D	D	
31. Prolymphocytic leukemia, B-cell	9833	D	D	D	D	S	D	D	D	D
32. Prolymphocytic leukemia, T-cell	9834	D	D	D	D	D	D	D	D	D
33. Precursor cell lymphoblastic leukemia, NOS	9835	S	S	D	D	D	D	D	D	
34. Precursor B-cell lymphoblastic leukemia	9836	S	S	D	D	D	D	D	D	D
35. Precursor T-cell lymphoblastic leukemia	9837	S	S	D	D	D	D	D	D	D
36. Myeloid leukemias	9840-9910	D	D	D	D	D	D	D	D	D
37. Therapy related acute myelogenous leuk.	9920	D	D	D	D	D	D	D	D	D
38. Myeloid sarcoma	9930	D	D	D	D	D	D	D	D	D
39. Acute panmyelosis	9931	D	D	D	D	D	D	D	D	<u>D</u>
40. Hairy cell leukemia	9940	D	<u>D</u>	D	<u>D</u>	<u>D</u>	D	<u>D</u>	<u>D</u>	<u>D</u>
41. Chronic myelomonocytic leukemia	9945	D	D	D	D	D	D	D	D	<u>D</u>
42. Juvenile myelomonocytic leukemia	9946	D S	D S	D	D D	D	D D	D D	D D	D D
43. NK-cell leukemia 44. Polycythemia vera	9948 9950	D D	D D	D D	D	D D	D	D	D	D
45. Chronic myeloproliferative disease	9960	D	D	D	D	D	D	D	D	D
46. Myelosclerosis	9961	D	D	D	D	D	D	D	D	<u>D</u>
47. Essential thrombocythemia	9962	D	D	D	D	D	D	D	D	D
48. Chronic neutrophilic leukemia	9963	D	D	D	D	D	D	D	D	D
49. Hypereosinophilic syndrome	9964	D	D	D	D	D	D	D	D	D
50. Refractory anemias	9980-9986	D	D	D	D	D	D	D	D	D
51. Therapy related MDS	9987	D	D	D	D	D	D	D	D	D
52. Myelodysplastic syndrome, NOS	9989	D	D	D	D	D	D	D	D	D
Key: S = one primary only; D = presumably a su	bsequent prima	ary	SE	ER Prog	ram, NO	CI. E-m	ail: seer	web@ir	ns.nci.ni	h.gov

Second Diagnosis Across →  ✓ First Diagnosis Down		10. <b>9690-9698</b> Follicular lymphoma	11. <b>9700-9701</b> MF, Sezary disease	12. <b>9702-9719</b> T/NK-cell lymphoma	13. <b>9727</b> Precursor Iym'blas lymph NOS	14. <b>9728</b> Precursor lym'blas lymph B-cl	15. <b>9729</b> Precursor lym'blas lymph T-cl	16. <b>9731-9734</b> Plasma cell tumors	17. <b>9740-9742</b> Mast cell tumors	18. <b>9750-9756</b> Histiocytosis; LCH
Malignant lymphoma, NOS	9590	S	s	S	S	S	S	S	S	S
Malignant lymphoma, non-Hodgkin, NOS	9591	S	S	S	S	S	S	 D	 D	
3. Composite HD/NHL	9596	S	S	S	S	S	S	D	D	D
4. Hodgkin lymphoma	9650-9667	D	D	D	D	D	D	D	D	D
5. Malignant lymphoma, small B lymphocytic	9670-9671	D	D	D	D	D	D	D	D	D
6. Mantle cell lymphoma	9673	D	D	D	D	D	D	D	D	D
7. Malignant lymphoma, diffuse, large B-cell	9670-9684	S	D	D	D	D	D	D	D	D
8. Burkitt lymphoma	9687	D	D	D	D	D	D	D	D	D
9. Marginal zone, B-cell lymphoma	9689-9699	D	D	D	D	D	D	D	D	D
10. Follicular lymphoma	9690-9698	S	D	D	D	D	D	D	D	D
11. Mycosis fungoides, Sezary disease	9700-9701	D	S	D	D	D	D	D	D	D
12. T/NK-cell non-Hodgkin lymphoma	9702-9719	D	D	S	D	D	D	D	D	D
13. Precursor lymphoblastic lymphoma, NOS	9727	D	D	D	S	S	S	D	D	D
14. Precursor B-cell lymphoblastic lymphoma	9728	D	D	D	S	S	D	D	D	D
15. Precursor T-cell lymphoblastic lymphoma	9729	<u>D</u>	<u>D</u>	<u>D</u>	<u>S</u>	D	S	D	<u>D</u>	<u>D</u>
16. Plasma cell tumors	9731-9734	D	D	D	D	D	D	S	D	<u>D</u>
17. Mast cell tumors	9740-9742	D	D	D	D	D D	D D	D	S	D
18. Histiocytosis/Langerhans cell histiocytosis 19. Dendritic cell sarcoma	9750-9756 9757-9758	D D	D D	D D	D D	D	D D	D D	D D	<b>S</b>
20. Immunoproliferative disease, NOS	9760	D	D	D	D	D	D	S	D	D D
21. Waldenstrom macroglobulinemia	9761			D	D		D	 D		
22. Heavy chain disease, NOS	9762	D	D	D	D	D	D	D	D	D
23. Immunoproliferative small intestinal disease	9764	D	D	D	D	D	D	S	D	D
24. Leukemia/Acute leukemia, NOS	9800-9801	D	D	S	S	S	S	D	D	
25. Acute biphenotypic leukemia	9805	S	S	S	S	S	S	D	D	D
26. Lymphocytic leukemia, NOS	9820	S	S	S	S	S	S			
27. BCLL/SLL	9823	D	D	D	D	D	D	D	D	
28. Burkitt cell leukemia	9826	D	D	D	D	D	D	D	D	D
29. Adult T-cell leukemia/lymphoma	9827	D	D	D	D	D	D	D	D	D
30. Prolymphocytic leukemia, NOS	9832	D	D	D	D	D	D	D	D	D
31. Prolymphocytic leukemia, B-cell	9833	D	D	D	D	D	D	D	D	D
32. Prolymphocytic leukemia, T-cell	9834	D	D	D	D	D	D	D	D	D
33. Precursor cell lymphoblastic leukemia, NOS	9835	D	D	D	S	S	S	D	D	D
34. Precursor B-cell lymphoblastic leukemia	9836	D	D	D	S	S	D	D	D	D
35. Precursor T-cell lymphoblastic leukemia	9837	D	D	D	S	D	S	D	D	_ <u>D</u> _
36. Myeloid leukemias	9840-9910	D	D	D	D	D	D	D	D	
37. Therapy related acute myelogenous leuk. 38. Myeloid sarcoma	9920 9930	D D	D D	D D	D D	D D	D D	D D	D D	D D
39. Acute panmyelosis	9931	D	D	D	D	D	D	D	D	D D
40. Hairy cell leukemia	9940	D	D	D	D	D	D	D	D	
41. Chronic myelomonocytic leukemia	9945	D	D	D	D	D	D	D	D	D
42. Juvenile myelomonocytic leukemia	9946	D	D	D	D	D	D	D	D	D
43. NK-cell leukemia	9948	D	D	S	D	D	D	D	D	D
44. Polycythemia vera	9950	D	D	D	D	D	D	D	D	D
45. Chronic myeloproliferative disease	9960	D	D	D	D	D	D	D	D	D
46. Myelosclerosis	9961	D	D	D	D	D	D	D	D	D
47. Essential thrombocythemia	9962	D	D	D	D	D	D	D	D	D
48. Chronic neutrophilic leukemia	9963	D	D	D	D	D	D	D	D	D
49. Hypereosinophilic syndrome	9964	D	D	D	D	D	D	D	D	D
50. Refractory anemias	9980-9986	D	D	D	D	D	D	D	D	D
51. Therapy related MDS	9987	D	D	D	D	D	D	D	D	D
52. Myelodysplastic syndrome, NOS	9989	D	D	D	D	D	D	D	D	D
Key: S = one primary only; D = presumably a su	bsequent prima	ary	SE	ER Proc	jram, NO	CI. E-ma	ail: seer	web@ir	ns.nci.n	h.gov

Second Diagnosis Across →  ✓ First Diagnosis Down		19. <b>9757-9758</b> Dendritic cell sarc	20. <b>9760</b> Immunoprolif dis	21. <b>9761</b> Waldenstrom macro	22. <b>9762</b> Heavy chain dis	23. <b>9764</b> Imm sm intest dis	24. <b>9800-9801</b> Leuk/Acu leuk NOS	25. <b>9805</b> Acute biphenotypic leuk	26. <b>9820</b> Lym'cyt leuk, NOS	27. <b>9823</b> BCLL/SLL
	0500									
1. Malignant lymphoma, NOS	9590 9591	S	S S	S	S	S	S S	S S	S	S
2. Malignant lymphoma, non-Hodgkin, NOS 3. Composite HD/NHL	9596	D D	S	S	S	S	S	D D	S	<u>S</u>
4. Hodgkin lymphoma	9650-9667	D	D D	 D	 D	D	 D	D	 D	
5. Malignant lymphoma, small B lymphocytic	9670-9671	D	D	S	D	D	D	S	S	S
6. Mantle cell lymphoma	9673	D	D	D	D	D	D	S	D	D
7. Malignant lymphoma, diffuse, large B-cell	9670-9684	D	S	S	S	S	D	S	S	S
8. Burkitt lymphoma	9687	D	D	D	D	D	S	S	S	D
9. Marginal zone, B-cell lymphoma	9689-9699	D	D	D	D	D	D	S	D	D
10. Follicular lymphoma	9690-9698	D	D	D	D	D	D	S	D	D
11. Mycosis fungoides, Sezary disease	9700-9701	D	D	D	D	D	D	S	S	D
12. T/NK-cell non-Hodgkin lymphoma	9702-9719	D	S	D	D	D	D	S	S	D
13. Precursor lymphoblastic lymphoma, NOS	9727	D	D	D	D	D	S	S	S	D
14. Precursor B-cell lymphoblastic lymphoma	9728	D	D	D	D	D	S	S	S	D
15. Precursor T-cell lymphoblastic lymphoma	9729	<u>D</u>	<u>D</u>	<u>D</u>	<u>D</u>	D	<u>S</u>	<u>S</u>	<u>S</u>	<u>D</u>
16. Plasma cell tumors	9731-9734	D	D	D	D	D	D	D	D	<u>D</u>
17. Mast cell tumors	9740-9742	D D	D D	D D	D D	D D	D D	D D	D D	D D
18. Histiocytosis/Langerhans cell histiocytosis 19. Dendritic cell sarcoma	9750-9756 9757-9758	S	D	D	D D	D	D D	D D	D D	<u>D</u>
20. Immunoproliferative disease, NOS	9760	 D	S	S	S	S	D	D	D	D D
21. Waldenstrom macroglobulinemia	9761	D	S	S	D	D	D	D	S	S
22. Heavy chain disease, NOS	9762	D	S	D	S	S	D	D	S	S
23. Immunoproliferative small intestinal disease	9764	D	S	D	S	S	D	D	D	D
24. Leukemia/Acute leukemia, NOS	9800-9801	D	D	D	D	D	S	S	S	D
25. Acute biphenotypic leukemia	9805	D	D	D	D	D	S	S	S	S
26. Lymphocytic leukemia, NOS	9820	D	S	S	S	D	S	S	S	S
27. BCLL/SLL	9823	D	S	D	D	D	D	S	S	S
28. Burkitt cell leukemia	9826	D	D	D	D	D	S	S	S	D
29. Adult T-cell leukemia/lymphoma	9827	D	D	D	D	D	D	S	S	D
30. Prolymphocytic leukemia, NOS	9832	D	D	D	D	D	D	S	S	S
31. Prolymphocytic leukemia, B-cell	9833	D	D	D	D	D	D	S	S	S
32. Prolymphocytic leukemia, T-cell	9834	D	D	D	D	D	D	S	S	D D
33. Precursor cell lymphoblastic leukemia, NOS	9835 9836	D D	D D	D D	D D	D D	S	S	S	<u>D</u>
34. Precursor B-cell lymphoblastic leukemia 35. Precursor T-cell lymphoblastic leukemia	9837	D	D	D	D	D	S	S	S	
36. Myeloid leukemias	9840-9910	D	D	D	D	D	S	S	D	D
37. Therapy related acute myelogenous leuk.	9920	D	D	D	D	D	S	S	D	D
38. Myeloid sarcoma	9930	D	D	D	D	D	S	S	D	D
39. Acute panmyelosis	9931	D	D	D	D	D	S	S	D	D
40. Hairy cell leukemia	9940	D	D	D	D	D	S	S	D	D
41. Chronic myelomonocytic leukemia	9945	D	D	D	D	D	S	S	D	D
42. Juvenile myelomonocytic leukemia	9946	D	D	D	D	D	S	S	D	D
43. NK-cell leukemia	9948	D	D	D	D	D	S	S	S	D
44. Polycythemia vera	9950	D	D	D	D	D	S	D	D	D
45. Chronic myeloproliferative disease	9960	D	D	D	D	D	S	S	D	<u>D</u>
46. Myelosclerosis	9961	D	D	D	D	D	S	S	D	
47. Essential thrombocythemia	9962 9963	D	D D	D D	D D	D D	S	D D	D D	D D
48. Chronic neutrophilic leukemia 49. Hypereosinophilic syndrome	9963	D D	D	D	D D	D	S	D	D D	<u>D</u>
50. Refractory anemias	9980-9986	D	D	D	D	D	S	S	D	D
51. Therapy related MDS	9987	D	D	D	D	D	S	S	D	D
52. Myelodysplastic syndrome, NOS	9989	D	D	D	D	D	S	S	D	D
Key: S = one primary only; D = presumably a su							ail: seer			
5 one primary only, b prosumably a su	2004aont prime	·· <u>J</u>	J.L.		, am, 110	··· = 1110	5001			gov

Second Diagnosis Across →		9826 Burkitt leukemia	9827 Adult T-cell leuk/lym	9832 Prolym leuk, NOS	9833 Prolym leuk, B-cell	9834 Prolym leuk, T-cell	9835 Precursor leukemia, NOS	9836 Precursor leukemia B-cell	9837 Precursor leukemia T-cell	<b>9840-9910</b> Myeloid leukemias
◆ First Diagnosis Down		28.	29.	30.	31.	32.	33.	34.	35.	36.
1. Malignant lymphoma, NOS	9590	S	S	S	S	S	S	S	S	S
2. Malignant lymphoma, non-Hodgkin, NOS	9591	S	S	D	D	D	S	S	S	D
3. Composite HD/NHL	9596	S	S	D	D	D	S	S	S	D
4. Hodgkin lymphoma 5. Malignant lymphoma, small B lymphocytic	9650-9667 9670-9671	D D	D D	D S	D S	D D	D D	D D	D D	D D
6. Mantle cell lymphoma	9673		D	 D	 	D		D	D	
7. Malignant lymphoma, diffuse, large B-cell	9670-9684	D	D	S	S	D	D	D	D	D
Burkitt lymphoma	9687	S	D	D	D	D	D	D	D	D
Marginal zone, B-cell lymphoma	9689-9699	D	D	D	D	D	D	D	D	
10. Follicular lymphoma	9690-9698	D	D	D	D	D	D	D	D	D
11. Mycosis fungoides, Sezary disease	9700-9701	D	D	D	D	D	D	D	D	D
12. T/NK-cell non-Hodgkin lymphoma	9702-9719	D	D	D	D	D	D	D	D	D
13. Precursor lymphoblastic lymphoma, NOS	9727	D	D	D	D	D	S	S	S	D
14. Precursor B-cell lymphoblastic lymphoma	9728	D	D	D	D	D	S	S	D	D
15. Precursor T-cell lymphoblastic lymphoma  16. Plasma cell tumors	9729 9731-9734	D D	D D	D D	D D	D D	S D	D D	S D	D D
17. Mast cell tumors	9740-9742	D	D	D	D	D	D	D	D	D
18. Histiocytosis/Langerhans cell histiocytosis	9750-9756	D	D	D	D	D	D	D	D	
19. Dendritic cell sarcoma	9757-9758	D	D	D	D	D	D	D	D	D
20. Immunoproliferative disease, NOS	9760	D	D	D	D	D	D	D	D	D
21. Waldenstrom macroglobulinemia	9761	D	D	D	D	D	D	D	D	D
22. Heavy chain disease, NOS	9762	D	D	D	D	D	D	D	D	D
23. Immunoproliferative small intestinal disease	9764	D	D	D	D	D	D	D	D	D
24. Leukemia/Acute leukemia, NOS	9800-9801	S	S	D	D	D	S	S	S	S
25. Acute biphenotypic leukemia	9805	S	S	S	S	S	S	S	S	S
26. Lymphocytic leukemia, NOS	9820	S	S	S	S	S	S	S	S	D
27. BCLL/SLL	9823	D	D	S	S	D	D	D	D	D
28. Burkitt cell leukemia	9826	<b>S</b>	D <b>S</b>	D D	D D	D D	D D	D D	D	D D
29. Adult T-cell leukemia/lymphoma 30. Prolymphocytic leukemia, NOS	9827 9832	D	D D	S	S	S	D	D	D D	D
31. Prolymphocytic leukemia, B-cell	9833		D	S	<u> </u>	 D	D	D		<u>D</u>
32. Prolymphocytic leukemia, T-cell	9834	D	S	S	D	S	D	D	D	
33. Precursor cell lymphoblastic leukemia, NOS	9835	D	D	D	D	D	S	S	S	D
34. Precursor B-cell lymphoblastic leukemia	9836	D	D	D	D	D	S	S	D	D
35. Precursor T-cell lymphoblastic leukemia	9837	D	D	D	D	D	S	D	S	D
36. Myeloid leukemias	9840-9910	D	D	D	D	D	D	D	D	S
37. Therapy related acute myelogenous leuk.	9920	D	D	D	D	D	D	D	D	S
38. Myeloid sarcoma	9930	D	D	D	D	D	D	D	D	S
39. Acute panmyelosis	9931	D	D	D	D	D	D	D	D	S
40. Hairy cell leukemia	9940	D	D	D	D	D	<u>D</u>	D	D	D
41. Chronic myelomonocytic leukemia 42. Juvenile myelomonocytic leukemia	9945 9946	D D	D D	D D	D D	D D	D D	D D	D D	S S
43. NK-cell leukemia	9948	D	D	D	D	D	D	D	D	
44. Polycythemia vera	9950	D	D	D	D	D	D	D	D	D
45. Chronic myeloproliferative disease	9960	D	D	D	D	D	D	D	D	S
46. Myelosclerosis	9961		D	D	D	D	D	D	D	S
47. Essential thrombocythemia	9962	D	D	D	D	D	D	D	D	S
48. Chronic neutrophilic leukemia	9963	D	D	D	D	D	D	D	D	S
49. Hypereosinophilic syndrome	9964	D	D	D	D	D	D	D	D	S
50. Refractory anemias	9980-9986	D	D	D	D	D	D	D	D	S
51. Therapy related MDS	9987	D	D	D	D	D	D	D	D	S
52. Myelodysplastic syndrome, NOS	9989	D	D	<u>D</u>	D	D	D	D	D	S
Key: S = one primary only; D = presumably a su	bsequent prima	ary	SE	ER Proc	ram, NO	CI. E-ma	ail: seer	web@ir	ns.nci.ni	h.gov

First Diagnosis Down   E   88   68   04   14   24   44	D D D
	D
1. Malignant lymphoma, NOS 9590 S S S S S D	
2. Malignant lymphoma, non-Hodgkin, NOS 9591 D D D D D D D D	
3. Composite HD/NHL         9596         D	
4. Hodgkin lymphoma         9650-9667         D<	D D
6. Mantle cell lymphoma 9673 D D D D D D D	D
7. Malignant lymphoma, diffuse, large B-cell 9670-9684 D D D D D D D	D
8. Burkitt lymphoma 9687 D D D D D D D	D
9. Marginal zone, B-cell lymphoma 9689-9699 D D D D D D	D
10. Follicular lymphoma 9690-9698 D D D D D D	D
11. Mycosis fungoides, Sezary disease 9700-9701 D D D D D D	D
12. T/NK-cell non-Hodgkin lymphoma 9702-9719 D D D D D D D	D
13. Precursor lymphoblastic lymphoma, NOS 9727 D D D D D D D	D
14. Precursor B-cell lymphoblastic lymphoma 9728 D D D D D D D D D D D D D D D D D D D	D
15. Precursor T-cell lymphoblastic lymphoma         9729         D<	D D
17. Mast cell tumors 9740-9742 D D D D D D D D	
18. Histiocytosis/Langerhans cell histiocytosis 9750-9756 D D D D D D D	D
19. Dendritic cell sarcoma  9757-9758 D D D D D D D  D D D D	D
20. Immunoproliferative disease, NOS 9760 D D D D D D	D
21. Waldenstrom macroglobulinemia 9761 D D D D D D	D
22. Heavy chain disease, NOS 9762 D D D D D D	D
23. Immunoproliferative small intestinal disease 9764 D D D D D D	D
24. Leukemia/Acute leukemia, NOS 9800-9801 S S D D S S D D	S
25. Acute biphenotypic leukemia 9805 S S S S S D	S
26. Lymphocytic leukemia, NOS         9820         D         <	D D
27. BCLL/SLL         9823         D	D D
29. Adult T-cell leukemia/lymphoma 9827 D D D D D D D	D
30. Prolymphocytic leukemia, NOS 9832 D D D D D D D	D
31. Prolymphocytic leukemia, B-cell 9833 D D D D D D	
32. Prolymphocytic leukemia, T-cell 9834 D D D D D D	D
33. Precursor cell lymphoblastic leukemia, NOS 9835 D D D D D D	D
34. Precursor B-cell lymphoblastic leukemia 9836 D D D D D D D	D
35. Precursor T-cell lymphoblastic leukemia 9837 D D D D D D D	D
36. Myeloid leukemias 9840-9910 S S S D S S D D	S
37. Therapy related acute myelogenous leuk.9920SSDSDD38. Myeloid sarcoma9930SSSDSSD	D S
38. Myeloid sarcoma         9930         S         S         D         S         D         D           39. Acute panmyelosis         9931         S         S         D         S         S         D         D	 D
40. Hairy cell leukemia 9940 D D D D D D	D
41. Chronic myelomonocytic leukemia 9945 S S D S D D	S
42. Juvenile myelomonocytic leukemia 9946 S S S D S S D D	D
43. NK-cell leukemia 9948 D D D D D S D	D
44. Polycythemia vera 9950 D D D D D S	S
45. Chronic myeloproliferative disease 9960 S S S D S D D	S
46. Myelosclerosis 9961 S S D S S D D	S
47. Essential thrombocythemia 9962 S S D D D D	S
48. Chronic neutrophilic leukemia9963SSDDD49. Hypereosinophilic syndrome9964SSSDSD	S S
49. Hypereosinophilic syndrome         9964         S         S         D         S         D         D           50. Refractory anemias         9980-9986         S         S         S         D         S         S         D         D	<u>S</u>
51. Therapy related MDS 9987 S S D S S D D	S
52. Myelodysplastic syndrome, NOS 9989 S S D S D D	
Key: S = one primary only; D = presumably a subsequent primary  SEER Program, NCI. E-mail: seerweb@ims.nci.ni	

Second Diagnosis Across →  ✓ First Diagnosis Down		46. <b>9961</b> Myelosclerosis	47. <b>9962</b> Essential thrombocythemia	48. <b>9963</b> Chr neutrophil leuk	49. <b>9964</b> Hypereosin syndr	50. <b>9980-9986</b> Refract anemias	51. <b>9987</b> Therapy rel MDS	52. <b>9989</b> Myelodys syn NOS	
Malignant lymphoma, NOS	9590					D	D	D	
Malignant lymphoma, non-Hodgkin, NOS	9591		D	D	D	D	D	D	
3. Composite HD/NHL	9596	D	D	D	D	D	D	D	
4. Hodgkin lymphoma	9650-9667	D	D	D	D	D	D	D	
5. Malignant lymphoma, small B lymphocytic	9670-9671	D	D	D	D	D	D	D	
6. Mantle cell lymphoma	9673	D			D			D	
7. Malignant lymphoma, diffuse, large B-cell	9670-9684	D	D	D	D	D	D	D	<u> </u>
8. Burkitt lymphoma	9687	D	D	D	D	D	D	D	
9. Marginal zone, B-cell lymphoma	9689-9699	D	D	D	D	D	D	D	
10. Follicular lymphoma	9690-9698	D	D	D	D	D	D	D	
11. Mycosis fungoides, Sezary disease	9700-9701	D	D	D	D	D	D	D	
12. T/NK-cell non-Hodgkin lymphoma	9702-9719	D	D	D	D	D	D	D	
13. Precursor lymphoblastic lymphoma, NOS	9727	D	D	D	D	D	D	D	
14. Precursor B-cell lymphoblastic lymphoma	9728	D	D	D	D	D	D	D	
15. Precursor T-cell lymphoblastic lymphoma	9729	D	D	D	D	D	D	D	
16. Plasma cell tumors	9731-9734	D	D	D	D	D	D	D	
17. Mast cell tumors	9740-9742	D	D	D	D	D	D	D	
18. Histiocytosis/Langerhans cell histiocytosis	9750-9756	D	D	D	D	D	D	D	
19. Dendritic cell sarcoma	9757-9758	D	D	D	D	D	D	D	
20. Immunoproliferative disease, NOS	9760	D	D	D	D	D	D	D	
21. Waldenstrom macroglobulinemia	9761	D	D	D	D	D	D	D	
22. Heavy chain disease, NOS	9762	D	D	D	D	D	D	D	
23. Immunoproliferative small intestinal disease	9764	D	D	D	D	D	D	D	
24. Leukemia/Acute leukemia, NOS	9800-9801	S	D	S	S	D	S	S	
25. Acute biphenotypic leukemia	9805	<u>S</u>	D	D	D	S	S	<u>S</u>	
26. Lymphocytic leukemia, NOS 27. BCLL/SLL	9820 9823	D D	D D	D D	D D	D D	D D	D D	
28. Burkitt cell leukemia	9826	D	D	D	D	D	D	D	
29. Adult T-cell leukemia/lymphoma	9827	D	D	D	D	D	D	D	
30. Prolymphocytic leukemia, NOS	9832	D	D	D	D	D	D	D	
31. Prolymphocytic leukemia, B-cell	9833	D	D	D	D	D	D	D	
32. Prolymphocytic leukemia, T-cell	9834	D	D	D	D	D	D	D	
33. Precursor cell lymphoblastic leukemia, NOS	9835	D	D	D	D	D	D	D	
34. Precursor B-cell lymphoblastic leukemia	9836	D	D	D	D	D	D	D	<u> </u>
35. Precursor T-cell lymphoblastic leukemia	9837	D	D	D	D	D	D	D	
36. Myeloid leukemias	9840-9910	S	S	S	S	D	S	S	
37. Therapy related acute myelogenous leuk.	9920	S	D	D	D	D	S	S	
38. Myeloid sarcoma	9930	S	S	S	D	D	S	S	
39. Acute panmyelosis	9931	S	D	D	D	D	S	S	
40. Hairy cell leukemia	9940	D	D	D	D	D	D	D	
41. Chronic myelomonocytic leukemia	9945	S	D	S	D	D	S	S	
42. Juvenile myelomonocytic leukemia	9946	S	D	D	D	D	S	S	
43. NK-cell leukemia	9948	D	D	D	D	D	D	D	
44. Polycythemia vera	9950	S	D	D	D	D	D	D	
45. Chronic myeloproliferative disease	9960	S	S	S	D	<u>D</u>	D	D	
46. Myelosclerosis	9961	S	S	S	D	D	S	S	
47. Essential thrombocythemia	9962	S	S	S	D	D	D	D	
48. Chronic neutrophilic leukemia	9963	S	S	S	D	D	D	D	
49. Hypereosinophilic syndrome	9964	S	D	D	S	D	D	D	
50. Refractory anemias	9980-9986	S	D	D	D	S	S	S	
51. Therapy related MDS	9987	S S	D D	D D	D D	S S	<b>S</b>	S S	
52. Myelodysplastic syndrome, NOS	9989								
Key: S = one primary only; D = presumably a subsequent primary SEER Program, NCI. E-mail: seerweb@ims.nci.nih.gov									

# COMPLETE DIAGNOSTIC TERMS FOR TABLE (BASED ON ICD-O-3)

1	9590	Malignant lymphoma, NOS
2	9591	Malignant lymphoma, non-Hodgkin, NOS
3	9596	Composite Hodgkin and non-Hodgkin lymphoma
4	9650-9667	Hodgkin lymphoma (all subtypes)
5	9670-9671	Malignant lymphoma, small B lymphocytic
6	9673	Mantle cell lymphoma
7	9675-9684	Malignant lymphoma, diffuse large B-cell
8	9687	Burkitt lymphoma
9	9689, 9699	Marginal zone B-cell lymphoma
10	9690-9698	Follicular lymphoma
11	9700-9701	Mycosis fungoides and Sezary syndrome
12	9702-9719	T/NK-cell non-Hodgkin lymphoma
13	9727	Precursor cell lymphoblastic lymphoma, NOS
14	9728	Precursor B-cell lymphoblastic lymphoma
15	9729	Precursor T-cell lymphoblastic lymphoma
16	9731-9734	Plasma cell tumors
17	9740-9742	Mast cell tumors
18	9750-9756	Histiocytosis/Langerhans cell histiocytosis
19	9757-9758	Dendritic cell sarcoma
20	9760	Immunoproliferative disease, NOS
21	9761	Waldenstrom macroglobulinemia
22	9762	Heavy chain disease, NOS
23	9764	Immunoproliferative small intestinal disease
24	9800-9801	Leukemia, NOS/Acute leukemia, NOS
25	9805	Acute biphenotypic leukemia
26	9820	Lymphoid leukemia, NOS
27	9823	B-cell chronic lymphocytic leukemia/small lymphocytic lymphoma
28	9826	Burkitt cell leukemia
29	9827	Adult T-cell leukemia/lymphoma (HTLV-1 positive)
30	9832	Prolymphocytic leukemia, NOS
31	9833	Prolymphocytic leukemia, B-cell type
32	9834	Prolymphocytic leukemia, T-cell type
33	9835	Precursor cell lymphoblastic leukemia, NOS
34	9836	Precursor B-cell lymphoblastic leukemia
35	9837	Precursor T-cell lymphoblastic leukemia
36	9840-9910	Myeloid leukemias
37	9920	Therapy related acute myelogenous leukemia
38	9930	Myeloid sarcoma
39	9931	Acute panmyelosis with myelofibrosis
40	9940	Hairy cell leukemia
41	9945	Chronic myelomonocytic leukemia, NOS
42	9946	Juvenile myelomonocytic leukemia
43	9948	Aggressive NK-cell leukemia
44	9950	Polycythemia vera
45 46	9960 9961	Chronic myeloproliferative disease, NOS
46 47		Myelosclerosis with myeloid metaplasia
47 49	9962	Essential thrombocythemia Chronic neutrophilic leukemia
48 49	9963 9964	Hypereosinophilic syndrome
49 50	9980-9986	Refractory anemias
50 51	9987	Therapy related myelodysplastic syndrome, NOS
52	9989	Myelodysplastic syndrome, NOS
52	3303	wydiadyspiadio dynaidine, ivod

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# APPENDIX F: CODING TIPS

The following tips are meant to help abstractors with some unusual or difficult coding situations. They are intended as general guidelines only. Ideas for performing quality control studies are listed in the last section of this appendix.

# 1. Overlapping lesions

- a. If the neoplasm overlaps the lip, oropharynx, and nasal cavity within the region of C00.0 to C14.2 and the point of origin cannot be assigned to any one of the categories, use C14.8.
- b. If the neoplasm overlaps digestive organs within the range of C15.0 to C26.0 and the point of origin cannot be assigned to any one of the categories, use C26.8.
- c. If the neoplasm overlaps respiratory and intrathoracic organs within the range of C30.0 to C39.0 and the point of origin cannot be assigned to any one of the categories, use C39.8.
- d. If the neoplasm overlaps bones, joints, and articular cartilage within the range of C40.0 to C41.4 and the point of origin cannot be assigned to any one of the categories, use C41.8.
- e. If the neoplasm overlaps female genital organs within the range of C51.0 to C57.7 or C58 and the point of origin cannot be assigned to any one of the categories, use C57.8.
- f. If the neoplasm overlaps male genital organs within the range of C60.0 to C63.7 and the point of origin cannot be assigned to any one of the categories, use C63.8.
- g. If the neoplasm overlaps urinary organs within the range of C64.9 to C68.1 and the point of origin cannot be assigned to any one of the categories, use C68.8.
- h. If the neoplasm overlaps the brain and central nervous system within the range of C70.0 to C72.5 and the point of origin cannot be assigned to any one of the categories, use C72.8.

# 2. Brain

- a. A brain lesion with a histology of adenocarcinoma is metastatic from a primary site elsewhere. Since adenocarcinoma does not originate in brain tissue, brain would not be the primary site. The histologies for brain primaries are generally in the 939 through 948 code range, the gliomas.
- b. Since there are no lymph nodes in the brain, regional lymph nodes positive and examined are to be coded 99 and 99, respectively.

# 3. Colon

- a. Familial polyposis is a systemic-type disease of the colon in which the entire colon has polyps. The polyps can occur in any or more than one segment. The diagnosis, adenocarcinoma in adenomatous polyposis coli (familial polyposis coli), should be considered one primary site of the colon, NOS (C18.9) with the histology 8220/3.
- b. If adenocarcinoma in situ is in an adenomatous polyp (8210/2) in the same section of the colon as an adenocarcinoma (8140/3), use the code that shows invasion (8140/3), rather than the higher histology code (8210/2).

Coding Tips Appendix F

## 4. Liver

a. Bile duct carcinoma (8160/3) is a specific histologic type usually found in the bile ducts of the liver (C22.1). Code the primary site to intrahepatic bile duct (C22.1), rather than extrahepatic bile duct (C24.0), unless the physician says "cystic" bile duct carcinoma.

- b. If histology is hepatocellular adenocarcinoma (8170/3), code primary site as liver (C22.0), even if it is not stated.
- c. Infiltrating duct carcinoma can occur in any organ with ducts, e.g., liver.
- d. If liver is coded as the primary site and the histology is not in the range of 8170-8180 or 8970, review the record to verify that liver is really the primary site and not a metastatic site. A liver tumor with a histology code 8140 (adenocarcinoma) usually represents metastasis to the liver from a primary site elsewhere.

# 5. Lung

- a. Pleural effusion, NOS (i.e., not stated whether benign or malignant) should be coded as malignant, and therefore distant in Summary staging. In AJCC TNM staging pleural effusion is not coded as distant and is coded as T4 only if determined to be "due to tumor."
- b. Make sure all cases of middle lobe, lung (C34.2) are coded to right side (laterality code 1).

# 6. Lymphomas

- a. A higher histology code generally means a more aggressive or more specific lymphoma.
- b. If nodular (or follicular) versus diffuse type of lymphoma is not stated, code as diffuse.
- c. A region of lymph nodes is not the same as a lymph node chain.
- d. There is a difference between the grade and the differentiation of lymphomas. Low, intermediate, and high grade lymphomas are not the same as Grade I, II, III, and IV.
  - Example: Intermediate grade malignant lymphoma, diffuse, poorly differentiated lymphocytic would be coded 9591/33. Code the grade/differentiation code based on the differentiation term, not the grade term.
- e. When the diagnosis is B-cell lymphoma with a stated grade/differentiation, code the B-cell over the differentiation code.
  - Example: Malignant lymphoma, diffuse lymphocytic, poorly differentiated, B-cell would be coded 9591/36.
- f. Stage II lymphomas, considered Regional, should be coded as Summary Stage 5 (Regional, NOS), rather than 2, 3, or 4. Beware of confusing Stage II with Summary Stage 2, as they are not the same.
- g. Use code 99 for both regional nodes examined and regional nodes positive for all lymphomas. (Refer to ROADS, page 129-130.)
- h. Use code 999 in the tumor size field for all Hodgkin and non-Hodgkin lymphomas. (Refer to ROADS, page 123.)

Appendix F Coding Tips

i. If a lymph node histology is adenocarcinoma (8140), the lymph node cannot be the primary site. Adenocarcinoma in a lymph node represents metastasis from adenocarcinoma originating in another site (the primary site).

# 7. Thyroid

If histology is follicular adenocarcinoma, NOS (8330/3) and the primary site is not stated, code the primary site as thyroid (C73.9).

## 8. Combination codes

a. Multiple or mixed histologies existing in one lesion may be coded to the combined histology code, even if the physician doesn't call the histology by its combined code name.

# b. Breast

If a patient has both an infiltrating duct carcinoma (8500/3) and a lobular carcinoma (8520/3), use the combined infiltrating duct and lobular carcinoma (8522/3).

Example: If there is an infiltrating duct carcinoma (8500/3) in the upper outer quadrant of breast (C50.4) and a lobular carcinoma, NOS (8520/3) in the lower inner quadrant (C50.3), code site to C50.9 and histology to 8522/3.

# 9. Miscellaneous Tips

a. Beware of misleading histologic names:

Intestinal type of adenocarcinoma occurs in stomach (C16.\_), not intestines (C17.\_).

A diagnosis of endometrial carcinoma should be coded as adenocarcinoma, NOS (8140) of the endometrium (C54.1). Do <u>not</u> code endometrial carcinoma as endometrioid carcinoma.

- b. If the histology type is transitional cell epidermoid carcinoma, there is a code for transitional cell carcinoma (8120/3) and a code for epidermoid carcinoma (8070/3). Use the higher histology code of 8120/3.
- c. Behavior code /1 (uncertain whether benign or malignant) refers to the behavior of the cell, not to the uncertainty of the physician as to what the behavior code should be.
- d. Only a few histologic types of "in situ" neoplasms are actually listed in *ICD-O-3*. The behavior code number "/2" could be attached to any of the four-digit code numbers in *ICD-O-3* if the "in situ" form of that neoplasm is diagnosed (*ICD-O-3*, page 20).
- e. Metastatic cells are more likely to be a higher grade (more poorly differentiated). Cells may start as well differentiated, but the longer the cells grow, they may change to poorly differentiated. They are multiplying and losing their differentiation at a greater rate, which is why poorly differentiated has a worse prognosis. Well differentiated looks more like a normal cell. Moderately differentiated is losing its distinction and architecture.
- f. Carcinoma, undifferentiated, NOS (8020/34) looks the same under a microscope as carcinoma, anaplastic, NOS (8021/34). Both are kept in the coding scheme for international comparisons.

Coding Tips Appendix F

# 10. Quality Control Ideas

a. Review all leukemia (9800 – 9948, excluding 9930) and multiple myeloma (9732) cases to make sure primary site is C42.1.

- b. Review all Summary Stage 7 cases to verify that there are Sites of Distant Metastasis (SDM) listed.
- c. Review all Summary Stage 3 an 4 cases to verify that they have positive regional lymph nodes.
- d. Review all cases that have positive regional lymph nodes. Verify that the Summary Stage is 3 or higher on these cases.
- e. Review the histology codes for prostate cancers. Most are adenocarcinoma (8140).
- f. Review all cases with a Summary Stage 0. The behavior code (5th digit of histology code) should be 2. Review all behavior codes of 2 and verify that Summary Stage is 0
- g. Review any cases with a behavior code of 6 or 9. These should not be in your registry. Most of the behavior codes 6 or 9 can be changed to a 3.
- h. Review cases where the year of diagnosis is the same as the year of birth. Verify that this is not an error.
- i. Compare the diagnosis year with the year of admission for consistency with the Class of Case. A patient diagnosed several years before the admission date cannot be a Class 0 or 1.
- j. Visually review paper abstracts before mailing to look for blanks and missing information.
- k. Review histology codes of oral cancers with site codes C00.0-C14.8. The majority (approximately 90%) should be squamous cell carcinomas (8050-8084).

Appendix F Coding Tips

HISTOLOGIC TYPE	PRIMARY SITE
Squamous cell carcinoma	Oral and nasal cavities Pharynx and larynx Trachea, bronchus, and lung Esophagus Cervix, vagina, and vulva Anus and penis Skin
Adenocarcinoma	Stomach Small intestine Colon and rectum Pancreas and gall bladder Endometrium and endocervix Breast Prostate
Transitional cell carcinoma	Bladder and urethra Renal pelvis and ureters
Hepatoma Liver cell carcinoma	Liver
Cholangiocarcinoma	Bile ducts (intrahepatic and extrahepatic)
Hypernephroma Renal cell carcinoma Wilms tumor	Kidney parenchyma
Seminoma	Testis
Dysgerminoma Cystadenocarcinoma Granulosa/theca cell carcinoma	Ovary
Liposarcoma	Adipose soft tissue
Fibrosarcoma	Fibrous soft tissue
Leiomyosarcoma	Smooth muscle, muscularis of organ walls
Rhabdomyosarcoma	Striated muscle, skeletal muscle
Mesothelial sarcoma	Pleura and peritoneum
Osteogenic sarcoma Ewing sarcoma	Bone
Chondrosarcoma	Cartilage
Lymphosarcoma Malignant lymphoma Hodgkin disease Reticulum cell sarcoma	Lymph nodes and other aggregates of lymphoid tissue
Lymphangiosarcoma	Lymph vessels
Hemangiosarcoma	Blood vessels
Leukemia Multiple myeloma	Bone marrow
Astrocytoma Glioblastoma multiforme Medulloblastoma	Brain
Melanoma	Skin Eye

# APPENDIX H: SITES NOT IN THE AJCC STAGING MANUAL

While the State Cancer Registry requires SEER General Summary Staging on <u>all</u> cases, the Commission on Cancer requires General Summary Stage only for sites that do not have AJCC site-specific staging schemes.

# Those sites are:

nose sites		OUDOITE				
SITE CODE	SITE GROUP	SUBSITE				
C17.3	Small Intestine	Meckel's diverticulum				
C25.4	Pancreas	Islets of Langerhans				
C26.0	Other and III-defined Digestive	Intestinal tract, NOS				
C26.8	Organs	Overlapping lesion of digestive system				
C26.9		Gastrointestinal tract, NOS				
C30.0	Nasal Cavity and Middle Ear	Nasal cavity				
C30.1		Middle ear				
C31.2	Accessory Sinuses	Frontal sinus				
C31.3		Sphenoid sinus				
C31.8		Overlapping lesion of accessory sinuses				
C31.9		Accessory sinus, NOS				
C33.9	Trachea	Trachea				
C37.9	Thymus	Thymus				
C39.0	Other and III-Defined Sites Within	Upper respiratory tract, NOS				
C39.8	Respiratory System and Intrathoracic Organs	Overlapping lesion of respiratory system and intrathoracic organs				
C39.9		III-defined sites within respiratory system				
C42.0	Hematopoietic and	Blood				
C42.1	Reticuloendothelial Systems	Bone marrow				
C42.2		Spleen				
C42.3		Reticuloendothelial system, NOS				
C42.4		Hematopoietic system, NOS				
C57.1	Other and Unspecified Female	Broad ligament				
C57.2	Genital Organs	Round ligament				
C57.3	1	Parametrium				
C57.4		Uterine adnexa				
C57.7		Other specified parts of female genital organs				
C57.8		Overlapping lesion of female genital organs				
C57.9		Female genital tract, NOS				
C58.9	Placenta	Placenta				
C63.0	Other and Unspecified Male Genital	Epididymis				
C63.1	Organs	Spermatic cord				
C63.7		Other specified parts of male genital organs				
C63.8		Overlapping lesion of male genital organs				
C63.9		Male genital organs, NOS				

SITE CODE	SITE GROUP	SUBSITE
C69.0	Eye, Brain and Other Parts of Central	Cornea, NOS
C69.9	Nervous System	Eye, NOS
C70.0	Meninges	Cerebral meninges
C70.1	_	Spinal meninges
C70.9		Meninges, NOS
C71.0	Brain	Cerebrum
C71.1		Frontal lobe
C71.2		Temporal lobe
C71.3		Parietal lobe
C71.4		Occipital lobe
C71.5		Ventricle, NOS
C71.6		Cerebellum, NOS
C71.7		Brain stem
C71.8		Overlapping lesion of brain
C71.9	1	Brain, NOS
C72.0	Spinal Cord, Cranial Nerves, and	Spinal cord
C72.1	Other Parts of Central Nervous	Cauda equina
C72.2	System	Olfactory nerve
C72.3		Optic nerve
C72.4		Acoustic nerve
C72.5		Cranial nerve, NOS
C72.8		Overlapping lesion of brain and central nervous system
C72.9		Nervous system, NOS
C74.0	Adrenal Gland	Cortex of adrenal gland
C74.1		Medulla of adrenal gland
C74.9		Adrenal gland, NOS
C75.0	Other Endocrine Glands and Related	Parathyroid gland
C75.1	Structures	Pituitary gland
C75.2		Craniopharyngeal duct
C75.3		Pineal gland
C75.4		Carotid body
C75.5		Aortic body and other paraganglia
C75.8		Overlapping lesion of endocrine glands and related structures
C75.9		Endocrine gland, NOS
C76.0	Other and III-Defined Sites	Head, face or neck, NOS
C76.1		Thorax, NOS
C76.2	†	Abdomen, NOS
C76.3		Pelvis, NOS
C76.4		Upper limb, NOS
C76.5		Lower limb, NOS

SITE CODE	SITE GROUP	SUBSITE
C76.7		Other ill-defined sites
C76.8		Overlapping lesion of ill-defined sites
C80.9	Unknown Primary Site	Unknown primary site

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### APPENDIX I: SURGERY TREATMENT CODES

#### **DEFINITIONS AND RULES**

Additional site-specific definitions and rules may be found with the site-specific codes.

### **Surgical Procedure of Primary Site**

a. If registry software allows only one procedure to be collected, document the most invasive surgical procedure for the primary site.

If registry software allows multiple procedures to be recorded, "Surgical Procedure of Primary Site" refers to the most invasive surgical procedure of the primary site.

- b. For codes 00 through 79, the code **positions** are hierarchical. The codes' numeric sequence may deviate from the order in which the codes are listed. Last-listed codes take precedence over codes listed above, because:
  - Within groups of codes, procedures are listed with increasing degrees of descriptive precision; and
  - Succeeding groups of codes define progressively more extensive forms of resection.

Example for RECTOSIGMOID (C19.9): A polypectomy with electrocautery is coded 22.

- 20 Local tumor excision, NOS
  - 26 Polypectomy
  - 27 Excisional biopsy

Combination of 20 or 26-27 WITH

- 21 Photodynamic therapy (PDT)
- 22 Electrocautery
- 23 Cryosurgery
- 24 Laser ablation
- 25 Laser excision
- 30 Wedge or segmental resection; partial proctosigmoidectomy, NOS 31 Plus resection of contiguous organs; example: small bowel, bladder
- c. Use codes 80 and 90 only if more precise information about the surgery is unavailable.
- d. Code 98 applies to specific tumors that cannot be clearly defined in terms of primary or non-primary site. Use code 98 for the following:
  - All hematopoietic/reticuloendothelial/immunoproliferative/myeloproliferative disease sites and/or histologies. WITH or WITHOUT surgical treatment:
  - All unknown and ill-defined disease sites, WITH or WITHOUT surgical treatment.
- e. Biopsies that remove all of the tumor and/or leave only microscopic margins are to be coded in "Surgical Procedure of Primary Site."
- f. Surgery to remove regional tissue or organs is coded in "Surgical Procedure of Primary Site" only if the tissue/organs are removed in continuity with the primary site, except where noted in Appendix I.
- g. If a previous surgical procedure to remove a portion of the primary site is followed by surgery to remove the remainder of the primary site, then code the total or final results. When multiple first course primary site surgical procedures are performed for a single tumor, the most extensive or definitive is the last performed, and the code should represent the cumulative effect of the separate procedures.

### **ORAL CAVITY (C00.0 - C06.9)**

Lip C00.0-C00.9, Base of Tongue C01.9, Other Parts of Tongue C02.0-C02.9, Gum C03.0-C03.9, Floor of Mouth C04.0-C04.9, Palate C05.0-C05.9, Other Parts of Mouth C06.0-C06.9

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 10 Local tumor destruction, NOS
  - 11 Photodynamic therapy (PDT)
  - 12 Electrocautery; fulguration (includes use of hot forceps for tumor destruction)
  - 13 Cryosurgery
  - 14 Laser

No specimen sent to pathology from surgical events 10-14.

- 20 Local tumor excision, NOS
  - 26 Polypectomy
  - 27 Excisional biopsy

Any combination of 20 or 26-27 WITH

- 21 Photodynamic therapy (PDT)
- 22 Electrocautery
- 23 Cryosurgery
- 24 Laser ablation
- 25 Laser excision

Specimen sent to pathology from surgical events 20-27.

30 Wide excision, NOS

## Code 30 includes:

Hemiglossectomy

Partial glossectomy

- 40 Radical excision of tumor, NOS
  - 41 Radical excision of tumor ONLY
  - 42 Combination of 41 WITH resection in continuity with mandible (marginal, segmental, hemi-, or total resection)
  - 43 Combination of 41 WITH resection in continuity with maxilla (partial, subtotal, or total resection)

## Codes 40-43 include:

Total glossectomy

Radical glossectomy

- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

#### **Terminology** (Robbins et al. 1991):

A <u>radical neck dissection</u> includes the removal of all ipsilateral cervical lymph node groups, i.e., lymph nodes from levels I through V (submental, submandibular, cranial jugular, medial jugular, caudal jugular, dorsal cervical nodes along the accessory nerve, and supraclavicular), and removal of the spinal accessory nerve, internal jugular vein and sternocleidomastoid muscle.

In a <u>modified radical neck dissection</u> the same lymph nodes are removed as in a radical neck dissection; however, one or more non-lymphatic structures are preserved.

A <u>selective</u> <u>neck</u> <u>dissection</u> is neck dissection with preservation of one or more lymph nodes group routinely removed in radical neck dissection.

## PAROTID AND OTHER UNSPECIFIED GLANDS (C07.9 – C08.9) Parotid Gland C07.9, Major Salivary Glands C08.0-C08.9

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 10 Local tumor destruction, NOS
  - 11 Photodynamic therapy (PDT)
  - 12 Electrocautery; fulguration (includes use of hot forceps for tumor destruction)
  - 13 Cryosurgery
  - 14 Laser

## No specimen sent to pathology from surgical events 10-14.

- 20 Local tumor excision, NOS
  - 26 Polypectomy
  - 27 Excisional biopsy

Any combination of 20 or 26-27 WITH

- 21 Photodynamic therapy (PDT)
- 22 Electrocautery
- 23 Cryosurgery
- 24 Laser ablation
- 25 Laser excision

## Specimen sent to pathology from surgical events 20-27.

- 30 Less than total parotidectomy, NOS; less than total removal of major salivary gland, NOS
  - 31 Facial nerve spared
  - 32 Facial nerve sacrificed
  - 33 Superficial lobe ONLY
    - 34 Facial nerve spared
    - 35 Facial nerve sacrificed
  - 36 Deep lobe (Total)
    - 37 Facial nerve spared
    - 38 Facial nerve sacrificed
- 40 Total parotidectomy, NOS; total removal of major salivary gland, NOS
  - 41 Facial nerve spared
  - 42 Facial nerve sacrificed
- 50 Radical parotidectomy, NOS; radical removal of major salivary gland, NOS
  - 51 WITHOUT removal of temporal bone
  - 52 WITH removal of temporal bone
  - 53 WITH removal of overlying skin (requires graft or flap coverage)
- 80 Parotidectomy, NOS
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

### PHARYNX (C09.0 - C14.0)

Tonsil C09.0-C09.9, Oropharynx C10.0-C10.9, Nasopharynx C11.0-C11.9, Pyriform Sinus C12.9, Hypopharynx C13.0-C13.9, Pharynx C14.0

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 10 Local tumor destruction, NOS
  - 11 Photodynamic therapy (PDT)
  - 12 Electrocautery; fulguration (includes use of hot forceps for tumor destruction)
  - 13 Cryosurgery
  - 14 Laser
  - 15 Stripping

## No specimen sent to pathology from surgical events 10-15.

- 20 Local tumor excision, NOS
  - 26 Polypectomy
  - 27 Excisional biopsy

Any combination of 20 or 26-27 WITH

- 21 Photodynamic therapy (PDT)
- 22 Electrocautery
- 23 Cryosurgery
- 24 Laser ablation
- 25 Laser excision
- 28 Stripping

### Specimen sent to pathology from surgical events 20-28.

- 30 Pharyngectomy, NOS
  - 31 Limited/partial pharyngectomy; tonsillectomy, bilateral tonsillectomy
  - 32 Total pharyngectomy
- 40 Pharyngectomy WITH laryngectomy OR removal of contiguous bone tissue, NOS (does NOT include total mandibular resection)
  - 41 WITH laryngectomy (laryngopharyngectomy)
  - 42 WITH bone
  - 43 WITH both 41 and 42
- 50 Radical pharyngectomy (includes total mandibular resection), NOS
  - 51 WITHOUT laryngectomy
  - 52 WITH laryngectomy
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

### **ESOPHAGUS (C15.0 - C15.9)**

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 10 Local tumor destruction, NOS
  - 11 Photodynamic therapy (PDT)
  - 12 Electrocautery; fulguration (includes use of hot forceps for tumor destruction)
  - 13 Cryosurgery
  - 14 Laser

## No specimen sent to pathology from surgical events 10-14.

- 20 Local tumor excision, NOS
  - 26 Polypectomy
  - 27 Excisional biopsy

Any combination of 20 or 26-27 WITH

- 21 Photodynamic therapy (PDT)
- 22 Electrocautery
- 23 Cryosurgery
- 24 Laser ablation
- 25 Laser excision

### Specimen sent to pathology from surgical events 20-27.

- 30 Partial esophagectomy
- 40 Total esophagectomy
- 50 Esophagectomy, NOS WITH laryngectomy and/or gastrectomy, NOS
  - 51 WITH laryngectomy
  - 52 WITH gastrectomy, NOS
  - 53 Partial gastrectomy
  - 54 Total gastrectomy
  - 55 Combination of 51 WITH any of 52-54
- 80 Esophagectomy, NOS
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

### STOMACH (C16.0 - C16.9)

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 10 Local tumor destruction, NOS
  - 11 Photodynamic therapy (PDT)
  - 12 Electrocautery; fulguration (includes use of hot forceps for tumor destruction)
  - 13 Cryosurgery
  - 14 Laser

## No specimen sent to pathology from surgical events 10-14.

- 20 Local tumor excision, NOS
  - 26 Polypectomy
  - 27 Excisional biopsy

Any combination of 20 or 26-27 WITH

- 21 Photodynamic therapy (PDT)
- 22 Electrocautery
- 23 Cryosurgery
- 24 Laser ablation
- 25 Laser excision

#### Specimen sent to pathology from surgical events 20-27.

- 30 Gastrectomy, NOS (partial, subtotal, hemi-)
  - 31 Antrectomy, lower (distal less than 40% of stomach)\*\*\*
  - 32 Lower (distal) gastrectomy (partial, subtotal, hemi-)
  - 33 Upper (proximal) gastrectomy (partial, subtotal, hemi-)

#### Code 30 includes:

Partial gastrectomy, including a sleeve resection of the stomach

Billroth I: anastomosis to duodenum (duodenostomy)

Billroth II: anastomosis to jejunum (jejunostomy)

- 40 Near-total or total gastrectomy, NOS
  - 41 Near-total gastrectomy
  - 42 Total gastrectomy

#### A total gastrectomy may follow a previous partial resection of the stomach.

- 50 Gastrectomy, NOS WITH removal of a portion of esophagus
  - 51 Partial or subtotal gastrectomy
  - 52 Near-total or total gastrectomy

## Codes 50-52 are used for gastrectomy resection when only portions of esophagus are included in procedure.

- 60 Gastrectomy with a resection in continuity with the resection of other organs, NOS\*\*\*
  - 61 Partial or subtotal gastrectomy, in continuity with the resection of other organs \*\*\*
  - 62 Near-total or total gastrectomy, in continuity with the resection of other organs \*\*\*
  - 63 Radical gastrectomy, in continuity with the resection of other organs \*\*\*

Codes 60-63 are used for gastrectomy resections with organs other than esophagus. Portions of esophagus may or may not be included in the resection.

80 Gastrectomy, NOS

## **STOMACH** C16.0-C16.9

- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

<sup>\*\*\*</sup> Incidental splenectomy NOT included

### **COLON (C18.0 - C18.9)**

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Note

Code removal/surgical ablation of single or multiple liver metastases under the data item *Surgical Procedure/Other Site*.

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 10 Local tumor destruction, NOS
  - 11 Photodynamic therapy (PDT)
  - 12 Electrocautery; fulguration (includes use of hot forceps for tumor destruction)
  - 13 Cryosurgery
  - 14 Laser

## No specimen sent to pathology from surgical events 10-14.

- 20 Local tumor excision, NOS
  - 27 Excisional biopsy
  - 26 Polypectomy, NOS
  - 28 Polypectomy endoscopic
  - 29 Polypectomy surgical excision

Any combination of 20 or 26-29 WITH

- 21 Photodynamic therapy (PDT)
- 22 Electrocautery
- 23 Cryosurgery
- 24 Laser ablation
- 25 Laser excision

### Specimen sent to pathology from surgical events 20-29.

- 30 Partial colectomy, segmental resection
  - 32 Plus resection of contiguous organ; example: small bowel, bladder
- 40 Subtotal colectomy/hemicolectomy (total right or left colon and a portion of transverse colon)
  - 41 Plus resection of contiguous organ; example: small bowel, bladder
- 50 Total colectomy (removal of colon from cecum to the rectosigmoid junction; may include a portion of the rectum)
  - 51 Plus resection of contiguous organ; example: small bowel, bladder
- 60 Total proctocolectomy (removal of colon from cecum to the rectosigmoid junction, including the entire rectum)
  - 61 Plus resection of contiguous organ; example: small bowel, bladder
- 70 Colectomy or coloproctectomy with resection of contiguous organ(s), NOS (where there is not enough information to code 32, 41, 51, or 61)

**Code 70 includes:** Any colectomy (partial, hemicolectomy, or total) WITH a resection of any other organs in continuity with the primary site. Other organs may be partially or totally removed. Other organs may include, but are not limited to, oophorectomy, partial proctectomy, rectal mucosectomy, or pelvic exenteration.

- 80 Colectomy, NOS
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

### **RECTOSIGMOID (C19.9)**

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

Code removal/surgical ablation of single or multiple liver metastases under the data item *Surgical Procedure/Other Site*.

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 10 Local tumor destruction, NOS
  - 11 Photodynamic therapy (PDT)
  - 12 Electrocautery; fulguration (includes use of hot forceps for tumor destruction)
  - 13 Cryosurgery
  - 14 Laser ablation

## No specimen sent to pathology from surgical events 10-14.

- 20 Local tumor excision, NOS
  - 26 Polypectomy
  - 27 Excisional biopsy

Combination of 20 or 26-27 WITH

- 21 Photodynamic therapy (PDT)
- 22 Electrocautery
- 23 Cryosurgery
- 24 Laser ablation
- 25 Laser excision

## Specimen sent to pathology from surgical events 20-27.

- 30 Wedge or segmental resection; partial proctosigmoidectomy, NOS
  - 31 Plus resection of contiguous organs; example: small bowel, bladder

#### Procedures coded 30 include, but are not limited to:

Anterior resection Hartmann's operation Low anterior resection (LAR) Partial colectomy, NOS Rectosigmoidectomy, NOS Sigmoidectomy

- 40 Pull through WITH sphincter preservation (colo-anal anastomosis)
- 50 Total proctectomy
- 51 Total colectomy
- 55 Total colectomy WITH ileostomy, NOS
  - 56 Ileorectal reconstruction
  - 57 Total colectomy WITH other pouch; example: Koch pouch
- 60 Total proctocolectomy, NOS
  - 65 Total proctocolectomy WITH ileostomy, NOS
  - 66 Total proctocolectomy WITH ileostomy and pouch

Removal of the colon from cecum to the rectosigmoid or a portion of the rectum.

70 Colectomy or proctocolectomy in continuity with other organs; pelvic exenteration

## RECTOSIGMOID C19.9

- 80 Colectomy, NOS; proctectomy, NOS
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

#### **Terminology**

<u>Duhamel operation</u>: A modification of a pull-through procedure with a longitudinal anastomosis between the proximal ganglionated segment of the colon and the rectum, leaving the rectum functional.

<u>Hartmann's operation</u>: A one-stage resection of primary rectal cancer with colostomy. The lower part of the sigmoid or the upper part of the rectum is resected distal to the neoplasm. The bowel is divided in the region of the descending colon. After the intervening segment of bowel has been removed, the proximal end of the descending colon is brought to the surface, as in a single-barreled colostomy. The proximal end of the distal segment is oversewn and left in place, leaving a blind rectal pouch.

<u>Miles' operation</u>: An abdominoperineal resection for cancer of the lower sigmoid and rectum, which includes permanent colostomy; removal of the pelvic colon, mesocolon, and adjacent lymph nodes; and wide perineal excision of the rectum and anus.

<u>Pull-through operation</u>: Permits removal of the desired portion of bowel (may include rectum, sigmoid, and, when indicated, descending colon and part of transverse colon) in one stage with retained sphincters, and end-to-end anastomosis. This operation is performed largely through the abdomen and does not require resection or removal of any part of the bony pelvis.

<u>Swenson's operation</u>: A pull-through resection with sphincter preservation.

Swenson's procedure: An abdomino-anal pull-through resection with partial internal sphincterectomy.

### **RECTUM (C20.9)**

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

Code removal/surgical ablation of single or multiple liver metastases under the data item *Surgical Procedure/Other Site*.

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 10 Local tumor destruction, NOS
  - 11 Photodynamic therapy (PDT)
  - 12 Electrocautery; fulguration (includes use of hot forceps for tumor destruction)
  - 13 Cryosurgery
  - 14 Laser

## No specimen sent to pathology from surgical events 10-14.

- 20 Local tumor excision, NOS
  - 27 Excisional biopsy
  - 26 Polypectomy

Any combination of 20 or 26-27 WITH

- 21 Photodynamic therapy (PDT)
- 22 Electrocautery
- 23 Cryosurgery
- 24 Laser ablation
- 25 Laser excision
- 28 Curette and fulguration

## Specimen sent to pathology from surgical events 20-28.

30 Wedge or segmental resection; partial proctectomy, NOS

#### Procedures coded 30 include, but are not limited to:

Anterior resection

Hartmann's operation

Low anterior resection (LAR)

Transsacral rectosigmoidectomy

- 40 Pull through WITH sphincter preservation (coloanal anastomosis)
- 50 Total proctectomy

#### Procedures coded 50 include but are not limited to:

Abdominoperineal resection (Miles' procedure)

- 60 Total proctocolectomy, NOS
- 70 Proctectomy or proctocolectomy with resection in continuity with other organs; pelvic exenteration
- 80 Proctectomy, NOS
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

## **Terminology**

<u>Duhamel operation</u>: A modification of a pull-through procedure with a longitudinal anastomosis between the proximal ganglionated segment of the colon and the rectum, leaving the rectum functional.

## RECTUM C20.9

<u>Hartmann's operation</u>: A one-stage resection of primary rectal cancer with colostomy. The lower part of the sigmoid or the upper part of the rectum is resected distal to the neoplasm. The bowel is divided in the region of the descending colon. After the intervening segment of bowel has been removed, the proximal end of the descending colon is brought to the surface, as in a single-barreled colostomy. The proximal end of the distal segment is oversewn and left in place, leaving a blind rectal pouch.

<u>Miles' operation</u>: An abdominoperineal resection for cancer of the lower sigmoid and rectum, which includes permanent colostomy; removal of the pelvic colon, mesocolon, and adjacent lymph nodes; and wide perineal excision of the rectum and anus.

<u>Pull-through operation</u>: Permits removal of the desired portion of bowel (may include rectum, sigmoid, and, when indicated, descending colon and part of transverse colon) in one stage with retained sphincters, and end-to-end anastomosis. This operation is performed largely through the abdomen and does not require resection or removal of any part of the bony pelvis.

Swenson's operation: A pull-through resection with sphincter preservation.

Swenson's procedure: An abdomino-anal pull-through resection with partial internal sphincterectomy.

### ANUS (C21.0 - C21.8)

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 10 Local tumor destruction, NOS
  - 11 Photodynamic therapy (PDT)
  - 12 Electrocautery; fulguration (includes use of hot forceps for tumor destruction)
  - 13 Cryosurgery
  - 14 Laser
  - 15 Thermal ablation

No specimen sent to pathology from surgical events 10-15.

- 20 Local tumor excision, NOS
  - 26 Polypectomy
  - 27 Excisional biopsy

Any combination of 20 or 26-27 WITH

- 21 Photodynamic therapy (PDT)
- 22 Electrocautery
- 23 Cryosurgery
- 24 Laser ablation
- 25 Laser excision

Specimen sent to pathology from surgical events 20-27.

- 60 Abdominal perineal resection, NOS (APR; Miles' procedure)
  - 61 APR and sentinel node excision
  - 62 APR and unilateral inguinal lymph node dissection
  - 63 APR and bilateral inguinal lymph node dissection

The lymph node dissection should also be coded under Scope of Regional Lymph Node Surgery or Scope of Regional Lymph Node Surgery at This Facility.

- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

### LIVER AND INTRAHEPATIC BILE DUCTS (C22.0 - C22.1)

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 10 Local tumor destruction, NOS
  - 11 Photodynamic therapy (PDT)
  - 12 Electrocautery; fulguration (includes use of hot forceps for tumor destruction)
  - 13 Cryosurgery
  - 14 Laser
  - 15 Alcohol (Percutaneous Ethanol Injection PEI)
  - 16 Heat-Radio-frequency Ablation (RFA)
  - 17 Other (ultrasound, acetic acid)

## No specimen sent to pathology from surgical events 10-17.

- 20 Wedge resection or segmental resection, NOS
  - 21 Wedge resection
  - 22 Segmental resection, NOS
    - 23 One
    - 24 Two
    - 25 Three
    - 26 Segmental resection AND local tumor destruction

## Specimen sent to pathology from surgical events 20-26.

- 30 Lobectomy, NOS
  - 36 Right lobectomy
  - 37 Left lobectomy
  - 38 Lobectomy AND local tumor destruction
- 50 Extended lobectomy, NOS (extended: resection of single lobe plus a segment of another lobe)
  - 51 Right lobectomy
  - 52 Left lobectomy
  - 59 Extended lobectomy AND local tumor destruction
- 60 Hepatectomy, NOS
  - 61 Total hepatectomy and transplant
- 65 Excision of a bile duct (for an intra-hepatic bile duct primary only)
  - 66 Excision of a bile duct PLUS partial hepatectomy
- 75 Bile duct and hepatectomy WITH transplant
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

## **PANCREAS (C25.0 - C25.9)**

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 25 Local excision of tumor, NOS
- 30 Partial pancreatectomy, NOS; example: distal
- 35 Local or partial pancreatectomy and duodenectomy
  - 36 WITHOUT distal/partial gastrectomy
  - 37 WITH partial gastrectomy (Whipple)
- 40 Total pancreatectomy
- 60 Total pancreatectomy and subtotal gastrectomy or duodenectomy
- 70 Extended pancreatoduodenectomy
- 80 Pancreatectomy, NOS
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

### LARYNX (C32.0 - C32.9)

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 10 Local tumor destruction, NOS
  - 11 Photodynamic therapy (PDT)
  - 12 Electrocautery; fulguration (includes use of hot forceps for tumor destruction)
  - 13 Cryosurgery
  - 14 Laser
  - 15 Stripping

#### No specimen sent to pathology from surgical events 10-15

- 20 Local tumor excision, NOS
  - 26 Polypectomy
  - 27 Excisional biopsy

Any combination of 20 or 26-27 WITH

- 21 Photodynamic therapy (PDT)
- 22 Electrocautery
- 23 Cryosurgery
- 24 Laser ablation
- 25 Laser excision
- 28 Stripping

## Specimen sent to pathology from surgical events 20-28.

- 30 Partial excision of the primary site, NOS; subtotal/partial laryngectomy, NOS; hemilaryngectomy, NOS
  - 31 Vertical laryngectomy
  - 32 Anterior commissure laryngectomy
  - 33 Supraglottic laryngectomy
- 40 Total or radical laryngectomy, NOS
  - 41 Total laryngectomy ONLY
  - 42 Radical laryngectomy ONLY
- 50 Pharyngolaryngectomy
- 80 Laryngectomy, NOS
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

#### Terminology (Robbins et al. 1991):

A radical neck dissection includes the removal of all ipsilateral cervical lymph node groups, i.e., lymph nodes from levels I through V (submental, submandibular, cranial jugular, medial jugular, caudal jugular, dorsal cervical nodes along the accessory nerve, and supraclavicular), and removal of the spinal accessory nerve, internal jugular vein and sternocleidomastoid muscle.

In a modified radical neck dissection the same lymph nodes are removed as in a radical neck dissection; however, one or more non-lymphatic structures are preserved.

A selective neck dissection is neck dissection with preservation of one or more lymph nodes group routinely removed in radical neck dissection.

### LUNG (C34.0 - C34.9)

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 19 Local tumor destruction or excision, NOS

Unknown whether a specimen was sent to pathology for surgical events coded 19 (principally for cases diagnosed prior to January 1, 2003).

- 15 Local tumor destruction, NOS
  - 12 Laser ablation or cryosurgery
  - 13 Electrocautery; fulguration (includes use of hot forceps for tumor destruction)

No specimen sent to pathology from surgical events 12-13 and 15.

- 20 Excision or resection of less than one lobe, NOS
  - 23 Excision, NOS
  - 24 Laser excision
  - 25 Bronchial sleeve resection ONLY
  - 21 Wedge resection
  - 22 Segmental resection, including lingulectomy

Specimen sent to pathology from surgical events 20-25.

30 Resection of lobe or bilobectomy, but less than the whole lung (partial pneumonectomy, NOS) 33 Lobectomy WITH mediastinal lymph node dissection

The lymph node dissection should also be coded under Scope of Regional Lymph Node Surgery or Scope of Regional Lymph Node Surgery at This Facility.

- 45 Lobe or bilobectomy extended, NOS
  - 46 WITH chest wall
  - 47 WITH pericardium
  - 48 WITH diaphragm
- 55 Pneumonectomy, NOS

56 WITH mediastinal lymph node dissection (radical pneumonectomy)

The lymph node dissection should also be coded under Scope of Regional Lymph Node Surgery or Scope of Regional Lymph Node Surgery at This Facility.

- 65 Extended pneumonectomy
  - 66 Extended pneumonectomy plus pleura or diaphragm
- 70 Extended radical pneumonectomy

The lymph node dissection should also be coded under Scope of Regional Lymph Node Surgery or Scope of Regional Lymph Node Surgery at This Facility.

- 80 Resection of lung, NOS
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

## HEMATOPOIETIC/RETICULOENDOTHELIAL/IMMUNOPROLIFERATIVE/MYELOPROLIFERATIVE DISEASE (C42.0, C42.1, C42.3, C42.4)

C42.0, C42.1, C42.3, C42.4 (with any histology) or

M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989 (with any site)

#### Code

98 All hematopoietic/reticuloendothelial/immunoproliferative/myeloproliferative disease sites and/or histologies, WITH or WITHOUT surgical treatment.

Surgical procedures for hematopoietic/reticuloendothelial/immunoproliferative/ myeloproliferative primaries are to be recorded using the data item *Surgical Procedure/Other Site* or *Surgical Procedure/Other Site* at *This Facility*.

# BONES, JOINTS, AND ARTICULAR CARTILAGE (40.0 – C41.9) PERIPHERAL NERVES AND AUTONOMIC NERVOUS SYSTEM (C47.0 – C47.9) CONNECTIVE, SUBCUTANEOUS, AND OTHER SOFT TISSUES (C49.0 – C49.9)

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 19 Local tumor destruction or excision, NOS

Unknown whether a specimen was sent to pathology for surgical events coded 19 (principally for cases diagnosed prior to January 1, 2003).

15 Local tumor destruction

No specimen sent to pathology from surgical event 15.

- 25 Local excision
- 26 Partial resection

Specimen sent to pathology from surgical events 25-26.

- 30 Radical excision or resection of lesion WITH limb salvage
- 40 Amputation of limb
  - 41 Partial amputation of limb
  - 42 Total amputation of limb
- 50 Major amputation, NOS
  - 51 Forequarter, including scapula
  - 52 Hindquarter, including ilium/hip bone
  - 53 Hemipelvectomy
  - 54 Internal hemipelvectomy
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

## **SPLEEN (C42.2)**

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 19 Local tumor destruction or excision, NOS.

  Unknown whether a specimen was sent to pathology for surgical events coded 19 (principally for cases diagnosed prior to January 1, 2003).
- 21 Partial splenectomy
- 22 Total splenectomy
- 80 Splenectomy, NOS
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

### **SKIN (C44.0 - C44.9)**

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 10 Local tumor destruction, NOS
  - 11 Photodynamic therapy (PDT)
  - 12 Electrocautery; fulguration (includes use of hot forceps for tumor destruction)
  - 13 Cryosurgery
  - 14 Laser ablation

## No specimen sent to pathology from surgical events 10-14.

- 20 Local tumor excision, NOS
  - 26 Polypectomy
  - 27 Excisional biopsy

Any combination of 20 or 26-27 WITH

- 21 Photodynamic therapy (PDT)
- 22 Electrocautery
- 23 Cryosurgery
- 24 Laser ablation
- 25 Laser excision

#### Specimen sent to pathology from surgical events 20-27.

- 30 Biopsy of primary tumor followed by a gross excision of the lesion (does not have to be done under the same anesthesia)
  - 31 Shave biopsy followed by a gross excision of the lesion
  - 32 Punch biopsy followed by a gross excision of the lesion
  - 33 Incisional biopsy followed by a gross excision of the lesion
  - 34 Mohs' surgery, NOS
  - 35 Mohs' with 1-cm margin or less
  - 36 Mohs' with more than 1-cm margin
- Wide excision or re-excision of lesion or minor (local) amputation with margins more than 1 cm, NOS. Margins MUST be microscopically negative.
  - 46 WITH margins more than 1 cm and less than or equal to 2 cm
  - 47 WITH margins greater than 2 cm

## If the excision does not have microscopically negative margins greater than 1 cm, use the appropriate code, 20-36.

- 60 Major amputation
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

### BREAST (C50.0 - C50.9)

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 19 Local tumor destruction, NOS

No specimen was sent to pathology for surgical events coded 19 (principally for cases diagnosed prior to January 1, 2003).

- 20 Partial mastectomy, NOS; less than total mastectomy, NOS
  - 21 Partial mastectomy WITH nipple resection
  - 22 Lumpectomy or excisional biopsy
  - 23 Re-excision of the biopsy site for gross or microscopic residual disease
  - 24 Segmental mastectomy (including wedge resection, quadrantectomy, tylectomy)

Procedures coded as 20-24 remove gross primary tumor and some of the breast tissue (breast-conserving or preserving). There may be microscopic residual tumor.

30 Subcutaneous mastectomy

Subcutaneous mastectomy is the removal of breast tissue without the nipple and areolar complex or overlying skin.

- 40 Total (simple) mastectomy, NOS
  - 41 WITHOUT removal of uninvolved contralateral breast
  - 43 Reconstruction, NOS
    - 44 Tissue
    - 45 Implant
    - 46 Combined (Tissue and Implant)
  - 42 WITH removal of uninvolved contralateral breast
  - 47 Reconstruction, NOS
    - 48 Tissue
    - 49 Implant
    - 75 Combined (Tissue and Implant)

A total (simple) mastectomy removes all breast tissue, the nipple, and areolar complex. An axillary dissection is not done.

For single primaries only, code removal of involved contralateral breast under the data item Surgical Procedure/Other Site or Surgical Procedure/Other Site at This Facility.

If contralateral breast reveals a second primary, each breast is abstracted separately. The surgical procedure is coded 41 for the first primary. The surgical code for the contralateral breast is coded to the procedure performed on that site.

- 50 Modified radical mastectomy
  - 51 WITHOUT removal of uninvolved contralateral breast
  - 53 Reconstruction, NOS
    - 54 Tissue
    - 55 Implant
    - 56 Combined (Tissue and Implant)
  - 52 WITH removal of uninvolved contralateral breast
    - 57 Reconstruction, NOS
    - 58 Tissue
    - 59 Implant
    - 63 Combined (Tissue and Implant)

BREAST C50.0-C50.9

Removal of all breast tissue, the nipple, the areolar complex, and variable amounts of breast skin in continuity with the axilla. The specimen may or may not include a portion of the pectoralis major muscle.

If contralateral breast reveals a second primary, it is abstracted separately. The surgical procedure is coded 51 for the first primary. The surgical code for the contralateral breast is coded to the procedure performed on that site.

For single primaries only, code removal of involved contralateral breast under the data item Surgical Procedure/Other Site or Surgical Procedure/Other Site at This Facility.

- 60 Radical mastectomy, NOS
  - 61 WITHOUT removal of uninvolved contralateral breast
    - 64 Reconstruction, NOS
    - 65 Tissue
    - 66 Implant
    - 67 Combined (Tissue and Implant)
  - 62 WITH removal of uninvolved contralateral breast
    - 68 Reconstruction, NOS
    - 69 Tissue
    - 73 Implant
    - 74 Combined (Tissue and Implant)
- 70 Extended radical mastectomy
  - 71 WITHOUT removal of uninvolved contralateral breast
  - 72 WITH removal of uninvolved contralateral breast
- 80 Mastectomy, NOS
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

#### **Terminology**

<u>Halsted radical mastectomy</u>: An en bloc resection of the entire breast and skin; pectoralis major and minor muscles; and contents of the axilla.

<u>Patey's and Dyson's operations</u>: Modified radical mastectomies with removal of the breast, pectoralis minor muscle, and axillary contents. The pectoralis major muscle remains intact.

Urban's extended radical mastectomy: Radical mastectomy and excision of internal mammary nodes.

### **CERVIX UTERI (C53.0 - C53.9)**

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

**For invasive cancers**, dilatation and curettage is coded as an incisional biopsy (02) under the data item *Surgical Diagnostic and Staging Procedure*.

#### Codes

- 00 None; no surgery of primary site, autopsy ONLY
- 10 Local tumor destruction, NOS
  - 11 Photodynamic therapy (PDT)
  - 12 Electrocautery; fulguration (includes use of hot forceps for tumor destruction)
  - 13 Cryosurgery
  - 14 Laser
  - 15 Loop Electrocautery Excision Procedure (LEEP)
  - 16 Laser ablation
  - 17 Thermal ablation

No specimen sent to pathology from surgical events 10-17.

- 20 Local tumor excision, NOS
  - 26 Excisional biopsy, NOS
  - 27 Cone biopsy
  - 24 Cone biopsy WITH gross excision of lesion
  - 29 Trachelectomy; removal of cervical stump; cervicectomy

Any combination of 20, 24, 26, 27, or 29 WITH

- 21 Electrocautery
- 22 Cryosurgery
- 23 Laser ablation or excision
- 25 Dilatation and curettage; endocervical curettage (for in situ only)
- 28 Loop Electrocautery Excision Procedure (LEEP)

Specimen sent to pathology from surgical events 20-29.

- 30 Total hysterectomy (simple, pan-) WITHOUT removal of tubes and ovaries Total hysterectomy removes both the corpus and cervix uteri and may also include a portion of vaginal cuff.
- 40 Total hysterectomy (simple, pan-) WITH removal of tubes and/or ovary

Total hysterectomy removes both the corpus and cervix uteri and may also include a portion of vaginal cuff.

- 50 Modified radical or extended hysterectomy; radical hysterectomy; extended radical hysterectomy
  - 51 Modified radical hysterectomy
  - 52 Extended hysterectomy
  - 53 Radical hysterectomy; Wertheim's procedure
  - 54 Extended radical hysterectomy
- 60 Hysterectomy, NOS, WITH or WITHOUT removal of tubes and ovaries
  - 61 WITHOUT removal of tubes and ovaries
  - 62 WITH removal of tubes and ovaries

CERVIX UTERI C53.0-C53.9

70 Pelvic exenteration

71 Anterior exenteration

Includes bladder, distal ureters, and genital organs WITH their ligamentous attachments and pelvic lymph nodes.

72 Posterior exenteration

Includes rectum and rectosigmoid WITH ligamentous attachments and pelvic lymph nodes.

73 Total exenteration

Includes removal of all pelvic contents and pelvic lymph nodes.

74 Extended exenteration

Includes pelvic blood vessels or bony pelvis

- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

### **Terminology**

<u>Wertheim's operation</u>: A radical abdominal hysterectomy for cancer of the cervix and uterus. The uterus and as much of the parametrial tissue as possible are removed, as well as a wide margin of the vagina.

### **CORPUS UTERI (C54.0 - C55.9)**

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

**For invasive cancers**, dilatation and curettage is coded as an incisional biopsy (02) under the data item *Surgical Diagnostic and Staging Procedure*.

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 19 Local tumor destruction or excision, NOS

Unknown whether a specimen was sent to pathology for surgical events coded 19 (principally for cases diagnosed prior to January 1, 2003).

- 10 Local tumor destruction, NOS
  - 11 Photodynamic therapy (PDT)
  - 12 Electrocautery; fulguration (includes use of hot forceps for tumor destruction)
  - 13 Cryosurgery
  - 14 Laser
  - 15 Loop Electocautery Excision Procedure (LEEP)
  - 16 Thermal ablation

No specimen sent to pathology from surgical events 10-16.

- 20 Local tumor excision, NOS; simple excision, NOS
  - 24 Excisional biopsy, NOS
  - 25 Polypectomy
  - 26 Myomectomy

Any combination of 20 or 24-26 WITH

- 21 Electrocautery
- 22 Cryosurgery
- 23 Laser ablation or excision

#### Specimen sent to pathology from surgical events 20-26.

- 30 Subtotal hysterectomy/supracervical hysterectomy/fundectomy WITH or WITHOUT removal of tube(s) and ovary(ies)
  - 31 WITHOUT tube(s) and ovary(ies)
  - 32 WITH tube(s) and ovary(ies)
- 40 Total hysterectomy (simple, pan-) WITHOUT removal of tube(s) and ovary(ies)

  Removes both the corpus and cervix uteri. It may also include a portion of the vaginal cuff.
- Total hysterectomy (simple, pan-) WITH removal of tube(s) and/or ovary(ies)

  Removes both the corpus and cervix uteri. It may also include a portion of the vaginal cuff.
- 60 Modified radical or extended hysterectomy; radical hysterectomy; extended radical hysterectomy
  - 61 Modified radical hysterectomy
  - 62 Extended hysterectomy
  - 63 Radical hysterectomy; Wertheim's procedure
  - 64 Extended radical hysterectomy
- 65 Hysterectomy, NOS, WITH or WITHOUT removal of tube(s) and ovary(ies)
  - 66 WITHOUT removal of tube(s) and ovary(ies)
  - 67 WITH removal of tube(s) and ovary(ies)

CORPUS UTERI C54.0-C55.9

#### 75 Pelvic exenteration

76 Anterior exenteration

Includes bladder, distal ureters, and genital organs WITH their ligamentous attachments and pelvic lymph nodes.

77 Posterior exenteration

Includes rectum and rectosigmoid WITH ligamentous attachments and pelvic lymph nodes.

78 Total exenteration

Includes removal of all pelvic contents and pelvic lymph nodes.

79 Extended exenteration

Includes pelvic blood vessels or bony pelvis

- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

### **Terminology**

<u>Wertheim's operation</u>: A radical abdominal hysterectomy for cancer of the cervix and uterus. The uterus and as much of the parametrial tissue as possible are removed, as well as a wide margin of the vagina.

### **OVARY (C56.9)**

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 17 Local tumor destruction, NOS

No specimen sent to pathology from surgical event 17.

- 25 Total removal of tumor or (single) ovary, NOS
  - 26 Resection of ovary (wedge, subtotal, or partial) ONLY, NOS; unknown if hysterectomy done 27 WITHOUT hysterectomy
    - 28 WITH hysterectomy

Specimen sent to pathology from surgical events 25-28.

- 35 Unilateral (salpingo-) oophorectomy; unknown if hysterectomy done
  - 36 WITHOUT hysterectomy
  - 37 WITH hysterectomy
- 50 Bilateral (salpingo-) oophorectomy; unknown if hysterectomy done
  - 51 WITHOUT hysterectomy
  - 52 WITH hysterectomy
- 55 Unilateral or bilateral (salpingo-) oophorectomy WITH OMENTECTOMY, NOS (partial or total); unknown if hysterectomy done
  - 56 WITHOUT hysterectomy
  - 57 WITH hysterectomy
- 60 Debulking; cytoreductive surgery, NOS
  - 61 WITH colon (including appendix) and/or small intestine resection (not incidental)
  - 62 WITH partial resection of urinary tract (not incidental)
  - 63 Combination of 61 and 62

Debulking is a partial or total removal of the tumor mass and can involve the removal of multiple organ sites. It may include removal of ovaries and/or the uterus (a hysterectomy). The pathology report may or may not identify ovarian tissue. A debulking is usually followed by another treatment modality such as chemotherapy.

- 70 Pelvic exenteration, NOS
  - 71 Anterior exenteration

Includes bladder, distal ureters, and genital organs WITH their ligamentous attachments and pelvic lymph nodes.

72 Posterior exenteration

Includes rectum and rectosigmoid WITH ligamentous attachments and pelvic lymph nodes.

73 Total exenteration

Includes removal of all pelvic contents and pelvic lymph nodes.

74 Extended exenteration

Includes pelvic blood vessels or bony pelvis

OVARY C56.9

- 80 (Salpingo-) oophorectomy, NOS
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

### PROSTATE (C61.9)

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

**Do not code** an orchiectomy in this field. For prostate primaries, orchiectomies are coded in the data item *Hematologic Transplant and Endocrine Procedures*.

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 18 Local tumor destruction or excision, NOS
- 19 Transurethral resection (TURP), NOS

Unknown whether a specimen was sent to pathology for surgical events coded 18 or 19 (principally for cases diagnosed prior to January 1, 2003).

- 10 Local tumor destruction, NOS
  - 14 Cryoprostatectomy
  - 15 Laser ablation
  - 16 Hyperthermia
  - 17 Other method of local tumor destruction

No specimen sent to pathology from surgical events 10-17.

- 20 Local tumor excision, NOS
  - 21 Transurethral resection (TURP), NOS
  - 22 TURP cancer is incidental finding during surgery for benign disease
  - 23 TURP patient has suspected/known cancer

Any combination of 20-23 WITH

- 24 Cryosurgery
- 25 Laser
- 26 Hyperthermia

Specimen sent to pathology from surgical events 20-26.

- 30 Subtotal, segmental, or simple prostatectomy, which may leave all or part of the capsule intact
- 50 Radical prostatectomy, NOS; total prostatectomy, NOS Excised prostate, prostatic capsule, ejaculatory ducts, seminal vesicle(s) and may include a narrow cuff of bladder neck.
- 70 Prostatectomy WITH resection in continuity with other organs; pelvic exenteration Surgeries coded 70 are any prostatectomy WITH resection in continuity with any other organs. The other organs may be partially or totally removed. Procedures may include, but are not limited to, cystoprostatectomy, radical cystectomy, and prostatectomy.
- 80 Prostatectomy, NOS
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

## **TESTIS (C62.0 - C62.9)**

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 12 Local tumor destruction, NOSNo specimen sent to pathology from surgical event 12.
- 20 Local or partial excision of testicle

  Specimen sent to pathology from surgical event 20.
- 30 Excision of testicle WITHOUT cord
- 40 Excision of testicle WITH cord or cord not mentioned (radical orchiectomy)
- 80 Orchiectomy, NOS (unspecified whether partial or total testicle removed)
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

## KIDNEY, RENAL PELVIS, AND URETER (C64.9 – C66.9) Kidney C64.9, Renal Pelvis C65.9, Ureter C66.9

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 10 Local tumor destruction, NOS
  - 11 Photodynamic therapy (PDT)
  - 12 Electrocautery; fulguration (includes use of hot forceps for tumor destruction)
  - 13 Cryosurgery
  - 14 Laser
  - 15 Thermal ablation

No specimen sent to pathology from surgical events 10-15.

- 20 Local tumor excision, NOS
  - 26 Polypectomy
  - 27 Excisional biopsy

Any combination of 20 or 26-27 WITH

- 21 Photodynamic therapy (PDT)
- 22 Electrocautery
- 23 Cryosurgery
- 24 Laser ablation
- 25 Laser excision

Specimen sent to pathology from surgical events 20-27.

30 Partial or subtotal nephrectomy (kidney or renal pelvis) or partial ureterectomy (ureter)

## Procedures coded 30 include, but are not to limited to:

Segmental resection

Wedge resection

40 Complete/total/simple nephrectomy - for kidney parenchyma

Nephroureterectomy

Includes bladder cuff for renal pelvis or ureter

50 Radical nephrectomy

May include removal of a portion of vena cava, adrenal gland(s), Gerota's fascia, perinephric fat, or partial/total ureter.

70 Any nephrectomy (simple, subtotal, complete, partial, simple, total, radical) in continuity with the resection of other organ(s) (colon, bladder)

The other organs, such as colon or bladder, may be partially or totally removed.

- 80 Nephrectomy, NOS Ureterectomy, NOS
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

### **BLADDER (C67.0 - C67.9)**

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 10 Local tumor destruction, NOS
  - 11 Photodynamic therapy (PDT)
  - 12 Electrocautery; fulguration (includes use of hot forceps for tumor destruction)
  - 13 Cryosurgery
  - 14 Laser
  - 15 Intravesical therapy
  - 16 Bacillus Calmette-Guerin (BCG) or other immunotherapy

No specimen sent to pathology from surgical events 10-16.

- 20 Local tumor excision, NOS
  - 26 Polypectomy
  - 27 Excisional biopsy

Combination of 20 or 26-27 WITH

- 21 Photodynamic therapy (PDT)
- 22 Electrocautery
- 23 Cryosurgery
- 24 Laser ablation
- 25 Laser excision

Specimen sent to pathology from surgical events 20-27.

- 30 Partial cystectomy
- 50 Simple/total/complete cystectomy
- 60 Radical cystectomy (male only)
  - 61 Radical cystectomy PLUS ileal conduit
  - 62 Radical cystectomy PLUS continent reservoir or pouch, NOS
  - 62 Radical cystectomy PLUS abdominal pouch (cutaneous)
  - 64 Radical cystectomy PLUS in situ pouch (orthotopic)
- 70 Pelvic exenteration, NOS
  - 71 Radical cystectomy (female only); anterior exenteration

A radical cystectomy in a female includes removal of bladder, uterus, ovaries, entire vaginal wall, and entire urethra.

- 72 Posterior exenteration
- 73 Total exenteration

Includes removal of all pelvic contents and pelvic lymph nodes.

The lymph node dissection should also be coded under Scope of Regional Lymph Node Surgery or Scope of Regional Lymph Node Surgery at This Facility.

74 Extended exenteration

Includes pelvic blood vessels or bony pelvis.

- 80 Cystectomy, NOS
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

# BRAIN AND OTHER PARTS OF CENTRAL NERVOUS SYSTEM (C70.0 – C72.9) Meninges C70.0-C70.9; Brain C71.0-C71.9; Spinal Cord, Cranial Nerves, and Other Parts of Central Nervous System C72.0-C72.9

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

Do not code laminectomies for spinal cord primaries.

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 10 Tumor destruction, NOS

No specimen sent to pathology from surgical event 10.

Do not record stereotactic radiosurgery as tumor destruction. It should be recorded in the radiation treatment items.

- 20 Local excision (biopsy) of lesion or mass
  Specimen sent to pathology from surgical event 20.
- 40 Partial resection
- 55 Gross total resection
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

# **THYROID GLAND (C73.9)**

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 13 Local tumor destruction, NOS

No specimen sent to pathology from surgical event 13.

- 25 Removal of less than a lobe, NOS
  - 26 Local surgical excision
  - 27 Removal of a partial lobe ONLY

Specimen sent to pathology from surgical events 25-27.

- 20 Lobectomy and/or isthmectomy
  - 21 Lobectomy ONLY
  - 22 Isthmectomy ONLY
  - 23 Lobectomy WITH isthmus
- 30 Removal of a lobe and partial removal of the contralateral lobe
- 40 Subtotal or near total thyroidectomy
- 50 Total thyroidectomy
- 80 Thyroidectomy, NOS
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

# Terminology (Robbins et al. 1991):

A <u>radical neck dissection</u> includes the removal of all ipsilateral cervical lymph node groups, i.e., lymph nodes from levels I through V (submental, submandibular, cranial jugular, medial jugular, caudal jugular, dorsal cervical nodes along the accessory nerve, and supraclavicular), and removal of the spinal accessory nerve, internal jugular vein and sternocleidomastoid muscle.

In a <u>modified radical neck dissection</u> the same lymph nodes are removed as in a radical neck dissection; however, one or more non-lymphatic structures are preserved.

A <u>selective neck dissection</u> is neck dissection with preservation of one or more lymph nodes group routinely removed in radical neck dissection.

# **LYMPH NODES (C77.0 - C77.9)**

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 19 Local tumor destruction or excision, NOS

Unknown whether a specimen was sent to pathology for surgical events coded to 19 (principally for cases diagnosed prior to January 1, 2003).

15 Local tumor destruction, NOS

No specimen sent to pathology from surgical event 15.

25 Local tumor excision, NOS

Less than a full chain, includes an excisional biopsy of a single lymph node.

- 30 Lymph node dissection, NOS
  - 31 One chain
  - 32 Two or more chains
- 40 Lymph node dissection, NOS PLUS splenectomy
  - 41 One chain
  - 42 Two or more chains
- 50 Lymph node dissection, NOS and partial/total removal of adjacent organ(s)
  - 51 One chain
  - 52 Two or more chains
- 60 Lymph node dissection, NOS and partial/total removal of adjacent organ(s) PLUS splenectomy (Includes staging laparotomy for lymphoma.)
  - 61 One chain
  - 62 Two or more chains
- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

# **ALL OTHER SITES**

C14.2-C14.8	C31.0-C31.9	C51.0-C51.9	C68.0-C68.9
C17.0-C17.9	C33.9	C52.9	C69.0-C69.9
C23.9	C37.9	C57.0-C57.9	C74.0-C74.9
C24.0-C24.9	C38.0-C38.8	C58.9	C75.0-C75.9
C26.0-C26.9	C39.0-C39.9	C60.0-C60.9	
C30 0-C30 1	C48 0-C48 8	C63 0-C63 9	

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

#### Codes

- 00 None; no surgery of primary site; autopsy ONLY
- 10 Local tumor destruction, NOS
  - 11 Photodynamic therapy (PDT)
  - 12 Electrocautery; fulguration (includes use of hot forceps for tumor destruction)
  - 13 Cryosurgery
  - 14 Laser

No specimen sent to pathology from surgical events 10-14.

- 20 Local tumor excision, NOS
  - 26 Polypectomy
  - 27 Excisional biopsy

Any combination of 20 or 26-27 WITH

- 21 Photodynamic therapy (PDT)
- 22 Electrocautery
- 23 Cryosurgery
- 24 Laser ablation
- 25 Laser excision

# Specimen sent to pathology from surgical events 20-27.

- 30 Simple/partial surgical removal of primary site
- 40 Total surgical removal of primary site; enucleation
  - 41 Total enucleation (for eye surgery only)
- 50 Surgery stated to be "debulking"
- 60 Radical surgery

Partial or total removal of the primary site WITH resection in continuity (partial or total removal) with other organs.

- 90 Surgery, NOS
- 99 Unknown if surgery performed; death certificate ONLY

# UNKNOWN AND ILL-DEFINED PRIMARY SITES (C76.0 - C76.8, C80.9)

(Except for M-9750, 9760-9764, 9800-9820, 9826, 9831-9920, 9931-9964, 9980-9989)

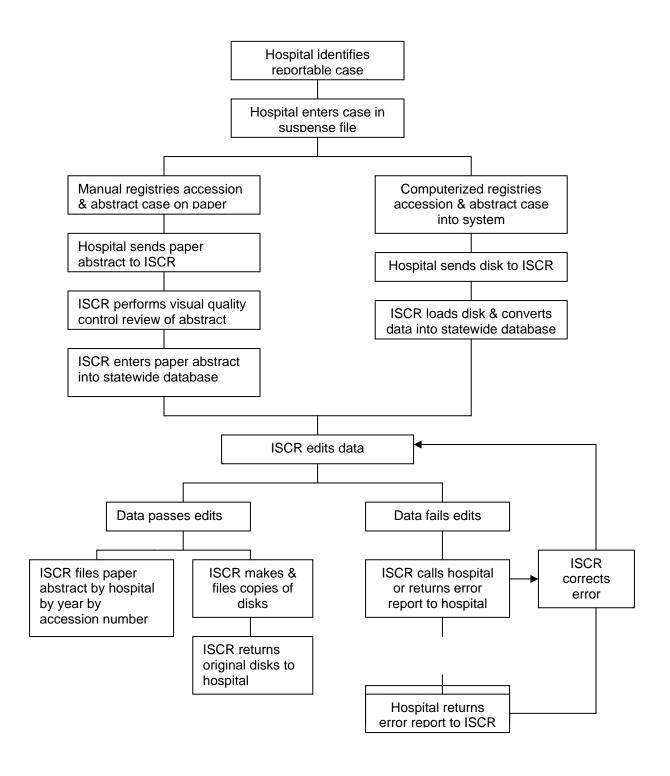
#### Code

98 All unknown and ill-defined disease sites, WITH or WITHOUT surgical treatment.

Surgical procedures for unknown and ill-defined primaries are to be recorded using the data item Surgical Procedure/Other Site or Surgical Procedure/Other Site at This Facility.

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APPENDIX J: FLOW CHART OF CANCER DATA AT THE INDIANA STATE CANCER REGISTRY (ISCR)



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# APPENDIX K: FIPS CODES FOR COUNTIES IN STATES ADJOINING INDIANA

State Name: Illinois

FIPS Code	County				
001	Adams	085	Jo Daviess	169	Schuyler
003	Alexander	087	Johnson		-
005	Bond	089	Kane	171	Scott
007	Boone			173	Shelby
009	Brown	091	Kankakee	175	Stark
		093	Kendall	177	Stephenson
011	Bureau	095	Knox	179	Tazewell
013	Calhoun	097	Lake		
015	Carroll	099	La Salle	181	Union
017	Cass	404		183	Vermilion
019	Champaign	101	Lawrence	185	Wabash
004	01:	103	Lee	187	Warren
021	Christian	105	Livingston	189	Washington
023	Clark	107	Logan	404	10/-
025	Clay	109	McDonough	191	Wayne
027	Clinton	444	Mallaga	193	White
029	Coles	111	McHenry McLean	195	Whiteside
021	Cook	113 115		197 199	Will Williamson
031 033	Crawford	115	Macon	199	vviillamson
035	Crawlord Cumberland	117	Macoupin Madison	201	Winnehage
033	DeKalbt	119	Madison	203	Winnebago Woodford
037	De Witt	121	Marion	203	vvoodioid
000	De vviit	123	Marshall		
041	Douglas	125	Mason		
043	DuPage	127	Massac		
045	Edgar	129	Menard		
047	Edwards	0			
049	Effingham	131	Mercer		
	3	133	Monroe		
051	Fayette	135	Montgomery		
053	Ford	137	Morgan		
055	Franklin	139	Moultrie		
057	Fulton				
059	Gallatin	141	Ogle		
		143	Peoria		
061	Greene	145	Perry		
063	Grundy	147	Piatt		
065	Hamilton	149	Pike		
067	Hancock		_		
069	Hardin	151	Pope		
074	Hardeney.	153	Pulaski		
071	Henderson	155	Putnam		
073	Henry	157	Randolph		
075	Iroquois	159	Richland		
077	Jackson	161	Rock Island		
079 081	Jasper	163 165	St. Clair Saline		
083	Jefferson Jersey	167			
003	Jersey	107	Sangamon		

State Name: Kentucky

FIPS Code	County				
001	Adair	081	Grant	161	Mason
003	Allen	083	Graves	163	Meade
005	Anderson	085	Grayson	165	Menifee
007	Ballard	087	Green	167	Mercer
009	Barren	089	Greenup	169	Metcalfe
011	Bath	091	Hancock	171	Monroe
013	Bell	093	Hardin	173	Montgomery
015	Boone	095	Harlan	175	Morgan
017	Bourbon	097	Harrison	177	Muhlenberg
019	Boyd	099	Hart	179	Nelson
021	Boyle	101	Henderson	181	Nicholas
023	Bracken	103	Henry	183	Ohio
025	Breathitt	105	Hickman	185	Oldham
027	Breckinridge	107	Hopkins	187	Owen
029	Bullitt	109	Jackson	189	Owsley
031	Butler Caldwell Calloway Campbell Carlisle	111	Jefferson	191	Pendleton
033		113	Jessamine	193	Perry
035		115	Johnson	195	Pike
037		117	Kenton	197	Powell
039		119	Knott	199	Pulaski
041	Carroll	121	Knox	201	Robertson
043	Carter	123	Larue	203	Rockcastle
045	Casey	125	Laurel	205	Rowan
047	Christian	127	Lawrence	207	Russell
049	Clark	129	Lee	209	Scott
051	Clay	131	Leslie	211	Shelby
053	Clinton	133	Letcher	213	Simpson
055	Crittenden	135	Lewis	215	Spencer
057	Cumberland	137	Lincoln	217	Taylor
059	Daviess	139	Livingston	219	Todd
061	Edmonson	141	Logan	221	Trigg
063	Elliott	143	Lyon	223	Trimble
065	Estill	145	McCracken	225	Union
067	Fayette	147	McCreary	227	Warren
069	Fleming	149	McLean	229	Washington
071	Floyd	151	Madison	231	Wayne
073	Franklin	153	Magoffin	233	Webster
075	Fulton	155	Marion	235	Whitley
077	Gallatin	157	Marshall	237	Wolfe
079	Garrard	159	Martin	239	Woodford

State Name: Michigan

FIPS Code	County				
001 003 005 007 009	Alcona Alger Allegan Alpena Antrim	081 083 085 087 089	Kent Keweenaw Lake Lapeer Leelanau	161 163 165	Washtenaw Wayne Wexford
011 013 015 017 019	Arenac Baraga Barry Bay Benzie	091 093 095 097 099	Lenawee Livingston Luce Mackinac Macomb		
021 023 025 027 029	Berrien Branch Calhoun Cass Charlevoix	101 103 105 107 109	Manistee Marquette Mason Mecosta Menominee		
031 033 035 037 039	Cheboygan Chippewa Clare Clinton Crawford	111 113 115 117 119	Midland Missaukee Monroe Montcalm Montmorency		
041 043 045 047 049	Delta Dickinson Eaton Emmet Genesee	121 123 125 127 129	Muskegon Newaygo Oakland Oceana Ogemaw		
051 053 055 057 059	Gladwin Gogebic Grand Traverse Gratiot Hillsdale	131 133 135 137 139	Ontonagon Osceola Oscoda Otsego Ottawa		
061 063 065 067 069	Houghton Huron Ingham Ionia Iosco	141 143 145 147 149	Presque Isle Roscommon Saginaw St. Clair St. Joseph		
071 073 075 077 079	Iron Isabella Jackson Kalamazoo Kalkaska	151 153 155 157 159	Sanilac Schoolcraft Shiawassee Tuscola Van Buren		

State Name: Ohio

FIPS Code	County				
001 003 005 007 009	Adams Allen Ashland Ashtabula Athens	081 083 085 087 089	Jefferson Knox Lake Lawrence Licking	161 163 165 167 169	Van Wert Vinton Warren Washington Wayne
011 013 015 017 019	Auglaize Belmont Brown Butler Carroll	091 093 095 097 099	Logan Lorain Lucas Madison Mahoning	171 173 175	Williams Wood Wyandot
021 023 025 027 029	Champaign Clark Clermont Clinton Columbiana	101 103 105 107 109	Marion Medina Meigs Mercer Miami		
031 033 035 037 039	Coshocton Crawford Cuyahoga Darke Defiance	111 113 115 117 119	Monroe Montgomery Morgan Morrow Muskingum		
041 043 045 047 049	Delaware Erie Fairfield Fayette Franklin	121 123 125 127 129	Noble Ottawa Paulding Perry Pickaway		
051 053 055 057 059	Fulton Gallia Geauga Greene Guernsey	131 133 135 137 139	Pike Portage Preble Putnam Richland		
061 063 065 067 069	Hamilton Hancock Hardin Harrison Henry	141 143 145 147 149	Ross Sandusky Scioto Seneca Shelby		
071 073 075 077 079	Highland Hocking Holmes Huron Jackson	151 153 155 157 159	Stark Summit Trumbull Tuscarawas Union		

# **GLOSSARY OF REGISTRY TERMS**

Terms in *italics* are defined within this glossary.

# Abbreviations Meaning

adj.	adjective
e.g.	for example
i.e.	that is
n.	noun
pl.	plural
V.	verb

#### Α

**abstract.** n. A summary, abridgement, or abbreviated record of pertinent information about a patient, the *cancer*, the *cancer-directed treatment*, and the outcome; the form or computer screen used to collect such information for each case. v: The act of collecting and recording cancer information from a health record.

accession. v. To enter a case into a cancer registry and assign it a number.

**accession number.** A unique 9-digit number assigned to the patient by the *registrar* indicating the year in which the patient was first seen for *cancer* at the reporting institution (first four digits) and the sequential order in which the patient was identified by the registry or *abstracted* into the database (last five digits). The number is used for all additional *primaries* the patient may develop, regardless of the year in which subsequent reportable *tumors* occur.

**accession register.** An annual, sequential listing of all reportable cases included in the *registry*. The accession register must include the *accession/sequence* number, patient name, *primary site*, and *date of initial diagnosis*. In a manual *registry*, it may be useful to include the *class of case* category. The accession register serves to identify, count, and evaluate the annual caseload.

acinus (pl. acini). A small saclike dilatation, particularly one found in various glands; synonymous with alveolus.

ACoS. American College of Surgeons.

ACS. American Cancer Society.

**adenocarcinoma.** A carcinoma derived from glandular tissue or in which the cells are arranged in the form of glands; a *malignant adenoma*.

adenocarcinoma in an adenomatous polyp. Adenocarcinoma in a glandular polyp of the colon.

**adenoma.** A benign epithelial tumor with a gland-like structure or in which the cells are clearly derived from glandular epithelium.

**adjunct.** An accessory or auxiliary agent or measure used in the *treatment* of disease or in other procedures.

**adjuvant therapy.** A treatment modality given in conjunction with another treatment modality, such as adjuvant *chemotherapy* given after *surgery* or *radiation* has destroyed the clinically detectable *cancer* cells, to prevent or delay *recurrence*.

adrenalectomy. Excision of adrenal glands.

adrenocorticotropic hormone (ACTH). A hormone that acts primarily on the adrenal cortex, stimulating its growth and its secretion of corticosteroids.

age specific rate. An incidence rate derived from analysis of data collected for a specific age group.

AJCC. American Joint Committee on Cancer.

allogenic cells. Cells belonging to or obtained from the same species but that are genetically different.

alphabetic. A term used to describe a data field that will accept letters only.

**alphanumeric.** A term used to describe a data field that will accept either letters or numbers but no special characters.

**analytic case.** A cancer case diagnosed and/or receiving all or part of the *first course* of treatment at the reporting facility. Analytic cases are eligible for inclusion in that registry's statistical reports of treatment efficacy and survival.

**anaplasia.** Reversion of cells to a more primitive or less differentiated form, a characteristic of *malignant tumors*; also called dedifferentiation.

**anastomosis.** A union or connection between two normally separate spaces or organs; typically used in describing a surgical connection between segments in the colon.

anatomic site. The place, position or location within the anatomy or structure of the organism.

**ancillary drugs.** Medications that enhance the effects of the *cancer-directed treatment* but do not directly affect the *cancer*. Ancillary drugs are <u>not</u> to be coded as cancer-directed treatment.

**annual report.** A publication produced on a yearly basis that describes the activities of an organization. For a *cancer* program, the report also includes statistics on the types of cancer diagnosed and treated at the facility.

autopsy. Postmortem pathologic examination of a body. Autopsy reports are used in casefinding.

#### В

basal cell. The predominant cell of the deepest layer of the epidermis.

**basement membrane.** A sheet of extracellular material interposed between cellular elements and underlying connective tissue. The sheet functions as a filtration barrier and a boundary that helps to generate and maintain tissue structure. In skin, it is the layer called basal lamina that marks the junction of the dermis and epidermis.

beam radiation. Radiation administered from an external source that may be either x-ray or cobalt.

**behavior.** Description of how a *tumor* acts in terms of whether it is *benign*, non*invasive*, *malignant*, or *metastatic*.

benign. Not malignant, not recurrent, favorable for recovery.

bilateral organs. Organs that occur as pairs, having a corresponding part on each side of the body.

biologic response modifier therapy. See immunotherapy.

**biopsy.** The removal of tissue for microscopic examination performed to establish a *diagnosis* and the characteristics of the *cancer*.

biostatistics. The application of statistics to the analysis of biological and medical data.

blastoma. A neoplasm composed of embryonic cells.

**blood dyscrasia.** A disease or pathologic condition of the blood.

**bone marrow transplant.** A type of treatment in which the patient's bone marrow is destroyed or reduced with high-dose *chemotherapy*, with or without total body irradiation, after which bone marrow is returned to the body to restore marrow and immune system function.

**borderline neoplasm.** A tumor with a behavior type that cannot be determined to be completely benign, yet which does not meet all criteria for malignancy.

**Bowen disease.** A squamous cell *carcinoma in situ* occurring usually on sun-exposed areas of skin, but sometimes found on mucous membranes; also called Bowen *precancerous* dermatosis and precancerous dermatitis.

**brachytherapy.** A type of *radiation therapy* where the radiation source is placed in direct contact with the *tumor*, for example, *cesium* capsules inserted into the uterus for treatment of endometrial *cancer*.

**BRM.** Biological Response Modifier, see immunotherapy.

# C

CA. Cancer.

cancer. A cellular tumor exhibiting the characteristics of anaplasia and invasion and the potential for metastasis.

cancer-directed treatment (or therapy). Treatment that is tumor directed. Its purpose is to modify, control, remove, or destroy primary or metastatic cancer tissue; excludes treatment solely for the relief of symptoms.

cancer (or tumor) registrar. An individual employed by a hospital or other institution for the purpose of recording, abstracting, and coding cancer cases. A cancer registrar collects and stores information on cancer patients, conducts periodic follow-up on these patients, and prepares reports on the data collected.

cancer (or tumor) registry. A data system designed for the collection, management, and analysis of data on persons with the *diagnosis* of a *malignant* disease (cancer).

carcinoma. A malignant tumor of epithelial origin.

carcinomatosis. Invasion of many organs of the body at the same time by metastases.

case. An occurrence of a *primary site* of a reportable *cancer*. One patient with two primary cancers represents two cases. See Chapter 3 and Appendix B for the State Cancer Registry's *reportable list*.

**casefinding.** Systematic identification of all reportable *cancer cases* in a defined population, such as patients of a hospital or patients seen in a physician's office; also called case ascertainment.

Caucasian. Of or relating to the white race as defined by law.

cautery. The application of an agent which destroys tissue by burning or searing.

CDC. Centers for Disease Control and Prevention.

cesium. A metallic element used in isotopic form as a radiation source for cancer-directed treatment.

**chemotherapy.** Treatment by administration of a chemical or drug that inhibits the reproduction of cancer cells and that does not achieve its effect through change of the hormone balance.

**class of case.** A registry term describing whether a case is *analytic* or *nonanalytic* based on where the initial *diagnosis* and *treatment* of the patient occurs.

clinical case. A cancer case for which the diagnosis is not microscopically confirmed.

*cluster.* An aggregation of cases of a disease or other health-related condition which are closely grouped in time and place.

**CoC.** Commission on Cancer of the American College of Surgeons.

code. Alphabetic and/or numeric characters representing information in a data set or report.

*colposcope.* A speculum for examining the vagina and cervix.

**comedocarcinoma.** A type of ductal beast *carcinoma* whose central cells are degenerated and easily expressed from the cut surface of the *tumor*.

computerized axial tomography (CT or CAT). A radiographic method of examining the body by creating an image from cross-sectional computerized "slices" of tissue. The computer calculates the degree of multiple x-ray beams that are not absorbed by all the tissue in its path and creates a computer image showing the geography and characteristics of tissue structures within solid organs.

**confidentiality.** The concept of maintaining the privacy of personal information obtained in the process of work.

**consultation.** Advice and counsel given about a patient by a physician who provides no *treatment* to that patient.

contiguous. Adjacent, touching, in contact with.

contralateral. Situated on or pertaining to the opposite side.

core data set. See required data set.

cryosurgery. Destruction of tissue by selective application of extreme cold.

CTR. Certified Tumor Registrar.

-cyte, cyto-. Greek combining forms meaning pertaining to a cell.

**cytology.** The study of cells, their origin, structure, function, and *pathology*; the *microscopic* examination of cells obtained by aspirations, washings, scrapings, and *smears*.

## D

DAM. Data Acquisition Manual (from the Commission on Cancer, ACoS), revised September 1994.

date of first recurrence. The point (month, day, and year) a cancer reappears after a disease-free interval.

**date of initial diagnosis.** The first time (month, day, year) that a recognized medical practitioner states that a patient has *cancer*, <u>usually</u> the date of first positive *tissue specimen*, although the first *diagnosis* can be *clinical* and may never be confirmed by *histology*.

date of last contact. The most recent point (month, day, and year) that a patient's vital status is known.

**death rate.** The number of deaths occurring over a given period of time divided by the number of persons at risk of dying during the same time period; also called *mortality rate*.

**debulking.** The surgical removal of as much *tumor* as possible, with or without total removal of the primary tumor, so that *adjuvant therapy* will be more effective; also called cytoreductive *surgery*.

definitive treatment. See cancer-directed treatment.

**demography.** The study of populations, especially with reference to size and density, fertility, mortality, growth, age distribution, migration, and vital statistics, and the interaction of all these with social and economic conditions.

derm-. Greek combining form meaning pertaining to skin.

diagnosis (pl. diagnoses). The identification of the presence, nature, and extent of a disease.

**diagnostic (or disease) index.** A listing of diagnoses for patients diagnosed or treated during a given time period. The listing is arranged in diagnostic groupings according to a specific coding system. The index is a source for *cancer casefinding*.

*differentiation.* The degree to which a *tumor* resembles the normal tissue from which it arose; also called *grade*. Differentiation reflects the aggressiveness of the tumor.

*direct extension.* A term used in *staging* to indicate *contiguous* growth of *tumor* from the *primary site* into an adjacent organ or surrounding tissue.

**direct visualization.** Gross observation of a cancer mass usually made at the time of surgery or autopsy.

disease free. Absence of any detectable cancer (including recurrence over a specified period of time).

dissection. The act of cutting apart or separating tissue.

**disseminated.** Scattered; distributed over a considerable area; in registry terms, describes a *tumor* that has spread throughout the body. Some tumors, such as *leukemias*, are disseminated at diagnosis. Others become disseminated as the result of *metastasis*.

**distant.** A term describing *stage of disease* for a *malignant neoplasm* that has spread to parts of the body remote from the primary tumor either by direct extension (beyond immediately adjacent organs or tissues) or by discontinuous *metastasis* (e.g., implantation or seeding) to distant organs, tissues, or via the lymphatic system to distant lymph nodes. Stage of disease for all *leukemias* and *multiple myelomas* is distant.

#### E

**-ectomy.** Suffix meaning excision or cutting out of an organ or part.

edit check. Computerized comparison of data fields for logic and accuracy.

en bloc resection. The removal of organs in one piece at one time.

**endocrine surgery.** Removal of an endocrine gland to stop growth of a *cancer* in another organ, when the hormonal product of the endocrine gland is implicated in the growth of the *tumor*, e.g., *orchiectomy* performed for cancer of the prostate.

endocrine therapy. See hormone therapy.

**endoscopy.** The visual inspection of any body cavity with an endoscope, an instrument for the examination of the interior of a hollow organ.

**endothelium.** The layer of epithelial cells that lines the cavities of the heart, blood and lymph vessels, serous cavities, and wall linings of hollow organs.

end results. The evaluation of cancer treatment through the analysis of patient survival after treatment.

EOD. Extent of disease.

excision. The act of removing, as of an organ or tumor, by cutting.

**excisional biopsy.** Surgical removal of an entire small *tumor*, for whatever purpose; a *biopsy*, performed to identify the cell type of the tumor, that removes the entire tumor.

**exenteration.** Surgical removal of the inner organs; the term is commonly used to indicate radical *excision* of the contents of a body cavity, as of the pelvis.

**exfoliative cytology.** *Microscopic* examination of cells shed from a body surface as a means of detecting *malignant* change.

extended data set. See optional data set.

**extent of disease.** Detailed description of how far the disease has spread from the *primary site* of a *cancer* at the time of *diagnosis*.

#### F

*first course.* The initial <u>planned</u> course of *treatment* or *therapy* for a specific *cancer*. Such treatment is typically initiated within four months following *diagnosis*, but may be initiated later than four months post-diagnosis (e.g., *consultation* irradiation given after completion of *chemotherapy*).

*flag.* In *registry* and computer terms, a data field that indicates a special status; for example, an incomplete *case* or a data field requiring an *override*.

*flow cytometry.* A special diagnostic technique used for DNA analysis of a *tumor*. The information, called DNA ploidy value, has prognostic clinical significance for some tumors.

focus (pl. foci). The chief center of a morbid process.

**follow-up.** Continued surveillance of a patient at specified intervals (usually twelve months) for the remainder of the patient's life following the initial *diagnosis* and *treatment* of a *cancer*. A documented contact with the patient, preferably through the attending physician, or through the spouse, a relative, or direct contact with the patient.

**frozen section.** A pathologic examination technique where part of a biopsy is quickly frozen, sliced thinly, and microscopically examined to determine the presence or absence of cancer cells. The technique is used for immediate diagnosis at the time of surgery so that, if indicated, more definitive surgical treatment can be completed at that time.

*fulguration.* Destruction of abnormal tissue by means of electric arc (indirect), or spark (direct), generated by high frequency current.

#### G

**glioma.** A *tumor*, usually associated with the brain, arising from the supporting structure of nervous tissue, including astrocytoma, oligodendroglioma, and ganglioglioma.

*grade.* The degree to which a *tumor* resembles the normal tissue from which it arose; also called *differentiation*. Grade reflects the aggressiveness of the tumor.

**gross anatomy.** That which deals with structures that can be distinguished with the unaided eye; also called *macroscopic* anatomy.

gross observation. Macroscopic examination; examination with the unaided eye; also called direct visualization.

# Н

*hematology.* The branch of medical science concerned with the study of the structure, functions, and disease of blood and blood-forming organs.

*hematopoietic.* Pertaining to the tissues that generate blood components, such as the bone marrow and stem cells.

*hepatic.* Pertaining to the liver.

*hermaphrodite.* An individual having the reproductive organs and many of the secondary sex characteristics of both sexes.

*histology.* The department of anatomy concerned with study of the minute structure, composition and function of the tissues; the microscopic structure of tissue.

*history of cancer.* The medical background for a patient who has been previously diagnosed with one or more *cancers*. The patient may or may not be *disease free*.

homolateral. Ipsilateral; same side.

**hormone therapy.** Cancer-directed treatment that interferes with the growth of cancer tissue by changing the hormonal balance of the patient. Hormone therapy may involve the use of hormones, antihormones, steroids, *endocrine surgery*, or endocrine radiation therapy.

*hyperbaric.* Characterized by greater than normal pressure or weight; for example, applied to oxygen under greater than normal atmospheric pressure.

**hypophysectomy.** Surgical removal of the hypophysis or pituitary gland.

ICD-9. International Classification of Diseases, ninth revision.

*ICD-9-CM.* International Classification of diseases, Clinical Modification, 9<sup>th</sup> Revision, 4<sup>th</sup> Edition. This edition has been adapted for use in the United States. All codes are compatible with ICD-9.

ICD-O. International Classification of Diseases for Oncology, 1976.

ICD-O-FT. International Classification of Diseases for Oncology, Field Trial Edition, March 1988.

ICD-O-2. International Classification of Diseases for Oncology, Second Edition, 1990.

ICD-O-3. International Classification of Diseases for Oncology, Third Edition, 2000.

**immunotherapy.** Cancer-directed treatment that boosts, directs, or restores the body's normal immune system and enhances the body's own ability to fight cancer. It is almost always used as an adjunct to surgery, radiation, and/or chemotherapy. Also called biologic response modifier therapy.

*incidence rates.* The number of new cases of a disease occurring in a period of time divided by the number of persons at risk of getting the disease during that time. The result is frequently multiplied by a base number such as 1,000 or 100,000.

incision. The act of cutting; a cut.

*incisional biopsy.* Surgical removal of a portion of a *tumor* performed to establish a *diagnosis* and the characteristics of the *cancer*.

*induration.* The quality of being hard; used to describe fibrous or connective tissue adjacent to the *tumor* and is to be interpreted as extension of the *malignant* growth.

*inpatient.* A hospital patient who is admitted for acute or critical care which is expected to require more than an overnight stay and whom the hospital classifies as an inpatient.

*in situ.* A term describing the *behavior* of a *neoplasm* which has all the characteristics of malignancy except invasion of neighboring tissues. It has not penetrated the *basement membrane*. A *diagnosis* of in situ behavior must be based on microscopic examination of tissue. Some synonyms are *intraductal*, *intraepithelial*, noninvasive, and noninfiltrating. Other terms meaning in situ are listed in Chapter 5, Item 38b.

*interferon.* Any of a family of agents with immuno-regulating effects and used to treat some types of *cancer.* Interferons are *biological response modifiers*.

intracystic. Within a cyst.

intraductal. Situated or occurring within the duct of a gland; in situ.

intraepithelial. Situated among the cells of the epithelium; in situ.

*intrathecal injection.* Injection of a substance into the cerebrospinal fluid surrounding the brain and spinal cord.

*invasion.* The infiltration and active destruction of tissue below the *basement membrane*, a characteristic of a *malignant* growth. (*invasive* adj.)

ipsilateral. Situated on or pertaining to the same side; homolateral.

# J

JCAHO. Joint Commission on Accreditation of Healthcare Organizations.

# Κ

#### L

*laser surgery.* Destruction of *cancer* tissue with a laser beam, most commonly used for vaginal or oral *tumors*.

*laterality.* Relationship to one side of the body or the other (left, right, both). Laterality is determined when the *primary site* is a *paired site*.

*left-justified.* A term describing characters in a data field when they are entered in the first space(s) to the left. Unused spaces at the right are left blank unless instructions specify otherwise.

lentigo maligna. A non-invasive melanotic freckle.

lentigo maligna melanoma. An invasive melanotic lesion.

lesion. Any pathological or traumatic discontinuity of tissue.

leukemia. A progressive, malignant disease of the blood-forming organs.

*lobular neoplasm.* A *neoplasm* resembling small lobes.

**localized.** A term describing stage of disease for an *invasive malignant neoplasm* that is confined entirely to the *organ of origin*.

*lymphadenopathy.* Disease of the *lymph nodes*, but not necessarily indicating *tumor* involvement.

*lymph node.* One of the accumulations of the lymphatic tissue organized as definite lymphatic organs, varying from 1 to 25 millimeters in diameter and situated along the course of lymphatic vessels.

*lymphoma.* Any *neoplastic* disorder of the lymphoid tissue. The term is often used alone to denote *malignant* lymphoma.

#### M

*macroscopic.* Visible to the unaided eye or without a microscope.

*macroscopic confirmation.* The process of supporting a *diagnosis* with evidence visible to the unaided eye.

*magnetic resonance imaging (MRI).* A diagnostic technique that uses an external magnetic field to visualize internal structures of the body by making it possible to distinguish between hydrogen atoms in different environments.

*malignant.* The tendency of a disease to become progressively worse and to result in death; having the properties of *anaplasia*, *invasion*, and *metastasis*; said of *tumors*.

*malignant melanoma.* A *malignant neoplasm* of melanocytes, usually developing from a nevus and consisting of black masses of cells with a marked tendency to *metastasize*.

*malignant tumor.* An uncontrolled, *invasive* growth capable of metastasizing (spreading to a distant part of the body). The opposite of *benign tumor*.

*master patient index.* The complete, alphabetized listing of every patient that has been *accessioned* into the *registry* since its *reference date*.

*medulloblastoma.* A radiosensitive *tumor* of undifferentiated neuroepithelial cells arising in the cerebellum.

*melanoma.* A *tumor* made up of melanin-pigmented cells (melanocytes). When used alone, the term refers to *malignant melanoma*.

**mesentery.** A membranous fold attaching organs to the body wall, most commonly used in reference to the fold attaching the small intestine to the dorsal body wall.

**mesocolon.** The section of *peritoneum* by which the colon is attached to the posterior abdominal wall. It is divided into ascending, transverse, descending, and sigmoid portions, according to the specific section of colon to which it gives attachment.

*metastasis* (*pl. metastases*). The transfer or spread of disease from the original *site* to another site not directly connected to it; the formation of a new *foci* of the disease. (v. *metastasize*. to spread.)

**metastatic.** Pertaining to the transfer (spread) of disease; spread to organs other than those listed in the *regional* areas; spread to other areas of the body; or spread to *lymph nodes* other than *regional lymph nodes*.

*micrometastasis.* Secondary *tumors* that are not visible to the unaided eye.

*microscopic confirmation.* The microscopic examination of tissue or cells removed from the *site* of a suspected *cancer* for the purpose of verifying a malignancy.

*morbidity rate.* An expression of the number of disease occurrences in a defined population during a specified interval of time.

*morphology.* The science concerned with the forms and structure of organisms; the form and structure of a particular organism, organ, or part.

**mortality rate.** An expression of the frequency of death occurring in a defined population during a specified interval of time.

*multiple myeloma.* A primary *malignant neoplasm* of plasma cells usually arising in the bone marrow and associated with skeletal destruction resulting in *pathological* fractures and bone pain.

*myelodysplastic syndrome.* A unique preleukemic condition in which the bone marrow shows progressive deterioration in red blood cell production, platelet formation, and white blood cell maturation.

myeloma. A tumor composed of a type of cell normally found in bone marrow.

# Ν

**NAACCR.** North American Association of Central Cancer Registries.

**National Center for Health Statistics.** The federal center for health statistics. It is one of the Centers for Disease Control and Prevention.

NCI. National Cancer Institute.

necropsy. The postmortem examination of a body; autopsy.

**neoadjuvant therapy.** Chemotherapy given prior to surgical resection or radiation therapy to reduce the bulk of a locally advanced primary cancer.

neoplasm. Any new and abnormal growth, such as a tumor. (neoplastic adj.)

NIH. National Institutes of Health.

**non-analytic case.** A cancer case that was diagnosed and received complete *first course* of treatment elsewhere prior to admission to the reporting facility, prior to the *cancer registry's reference date*, or diagnosed at *autopsy*. Such cases are generally not included in statistical reports of treatment and *survival*, but may be included in administrative reports.

**non cancer-directed treatment.** Treatment which prolongs the patient's life, alleviates pain, makes the patient comfortable, or prepares the patient for *cancer-directed treatment*. The treatment is not meant to destroy or control the *tumor* or delay the spread of disease.

NOS. Not otherwise specified.

**nuclear medicine.** The use of radioactive materials (isotopes) in *diagnosis* and *treatment* of disease; includes the application or internal use of radium, radioactive iodine, radioactive phosphorus, and radioactive gold, for example.

**numeric.** A term used to describe a data field that accepts numbers only.

#### 0

-oma. Suffix meaning tumor or neoplasm; swelling.

**omentum.** A fold of the *peritoneum* extending from the stomach to adjacent organs in the abdominal cavity.

oncology. The study of tumors and cancers.

oophorectomy. The removal of an ovary or ovaries.

**optional data set.** Additional data items that may be collected as an extension of a *required data set*. These additional data items are optional and are not required for certification purposes by the ACoS; also called extended data set.

orchiectomy. The removal of one or both testes.

organ of origin. Primary site of cancer.

**-oscopy.** Suffix meaning the act of examining or looking into an organ using an instrument called a scope.

osseous. Pertaining to bone.

**-ostomy.** Suffix meaning the surgical creation of an artificial opening into a hollow organ or a new opening between two such structures. The term "ostomy" is used alone when the opening is formed between two hollow organs or between one or more such organs and the abdominal wall for discharge of intestinal contents or of urine.

**other cancer-directed treatment.** Any cancer-directed treatment that is not appropriately assigned to the other specific treatment codes; includes any experimental or newly developed method of treatment differing greatly from accepted types of cancer therapy.

-otomy. Suffix meaning the operation of cutting, or incision.

**outpatient.** A hospital or clinic patient whose care and management is expected to require less than a one day stay and whom the hospital classifies as an "outpatient;" ambulatory (care) patient and short stay patient are terms for certain types of outpatients.

**override.** To indicate that an inconsistency (identified by *edit check*) between data elements has been reviewed and the information has been found to be correct.

#### Ρ

paired site. Bilateral organs; two corresponding body parts on opposite sides of the midline.

*palliative.* An adjective used to describe medical care intended to relieve symptoms or make the patient more comfortable, but not cure. Some of the treatments termed palliative fall within the definition of *cancer-directed treatment*, but others are excluded because they treat the patient but not the *cancer*. If the distinction cannot be discerned in the medical record, a physician must interpret the purpose of the treatment.

papillary. Pertaining to or resembling a papilla or nipple.

**Pap smear.** A type of *cytology* examination used for the detection and *diagnosis* of *malignant* and premalignant conditions of the female genital tract; Papanicolaou *smear* or test.

parietal. Of or pertaining to the walls of a cavity.

*parietal peritoneum.* Peritoneum lining the abdominal and pelvic walls, including the undersurface of the diaphragm.

pathologic, pathological. Of or relating to pathology, relating to or caused by disease.

*pathology.* The branch of medicine concerned with the study of the nature of disease, its causes, processes, and development, as well as the structural and functional changes in tissues and organs of the body which cause or are caused by disease.

**peritoneal.** Pertaining to the serous membrane lining the abdominopelvic walls and enveloping the *viscera*.

peritoneal fluid. Fluid from the serous membrane lining the abdominopelvic walls and viscera.

**peritoneum.** The serous membrane lining the abdominopelvic walls and enveloping the *viscera*; see also parietal peritoneum and *visceral peritoneum*.

*pleura (pl. pleurae).* The serous membrane enveloping the lungs and lining the thoracic cavity, completely enclosing the *pleural cavity*.

pleural cavity. The potential space between the parietal and visceral pleurae.

pleural fluid. Fluid from the serous membrane enveloping the lungs and lining the thoracic cavity.

*precancerous.* Pertaining to a condition that tends to become *malignant*.

**prednisone.** An adrenocortical steroid which, when used as part of a chemotherapeutic regimen, is considered *hormone therapy* for certain types of *cancer*.

primary site. The organ or tissue where a cancer originates; where the cancer started in the body.

primary site code. A three digit code designated for the specific anatomic site of the primary cancer.

#### Q

#### R

*radiation.* Energy transmitted in the form of rays, waves, or particles; usually referring to electromagnetic radiation when used without a modifier.

*radiation therapy (radiotherapy).* The *treatment* of disease by roentgen rays or other radiant energy. Use of external beams or internal radioactive implants independently; or before, during, or after *surgery* to kill *tumor* cells. Examples include *beam*, seed, needle, and radioactive drugs.

**radiology.** The science of radiant energy (such as x-rays) and radioactive substances; the use of radiant energy in the *diagnosis* and *treatment* of disease.

**rate** (incidence rate). A measure of the frequency with which an event (e.g., death or disease) occurs in relation to a unit of population over a specified period of time.

*rectosigmoid.* The upper portion of the rectum and the lower portion of the sigmoid colon.

**recurrence.** The return of a *cancer* after a clinically disease free interval.

**reference date.** The starting date for a *cancer registry* after which all eligible *cases* must be entered into the registry. The date must be January 1 of a given year.

**regional.** A term describing *stage of disease* for a *malignant neoplasm* that 1) has extended beyond the limits of the *organ of origin* directly into surrounding organs or tissues, 2) involves regional *lymph nodes* by way of the lymphatic system, or 3) has both regional extension and involvement of regional lymph nodes, with no evidence of *distant* spread.

registrar. See cancer registrar.

registry. See cancer registry.

**remission.** Complete or partial disappearance of the signs and symptoms of disease; the period in which a disease is under control.

**reportable list.** A list developed by a *cancer registry* that identifies all diagnoses and types of *cases* that are to be included in the registry and those that are to be excluded. It must include malignancies with a *behavior* code (fifth digit) of 2 or higher.

**required data set.** Minimum required information established by a cancer registry to be collected for each cancer case; also called core data set.

**resection.** Excision of a portion or all of an organ or other structure.

**retinoblastoma.** A malignant tumor arising from retinal germ cells and appearing in one or both eyes, usually in children under 5 years of age; *glioma* of the retina.

rhabdomyosarcoma. A malignant soft-tissue tumor of muscle origin.

**right-justified.** A term describing characters in a data field when they are entered in the last space(s) to the right. Unused spaces preceding the string of characters are left blank unless instructions specify otherwise.

RMCDS. Rocky Mountain Cancer Data Systems.

**ROADS.** Registry Operations and Data Standards (from Volume II, Standards of the Commission on Cancer, ACoS), revised January 1998.

# S

**salvage therapy.** Treatment given after the failure of *first cours*e of therapy in order to prolong survival or to improve quality of life; a second attempt to cure the patient; see also *subsequent treatment*.

**sarcoma.** A malignant tumor of mesodermal origin. The mesoderm is the embryonic germ layer from which the supporting structures of the body (bone, muscle, connective tissue) are derived.

**secondary site.** The organ to which a *malignant neoplasm* has spread from a *primary site*; *metastatic site*.

SEER. Surveillance, Epidemiology, and End Results Program of the National Cancer Institute.

**sentinel node.** The first node to receive drainage from a primary tumor. It is identified by injection of dye or radio label at the site of the primary tumor.

**sequence number.** A number assigned to a *case* in a *cancer registry* that indicates the chronological order of all independent, primary malignancies diagnosed during the life of the patient, whether the *tumors* exist at the same or at different times.

sex-specific rate. An incidence or death rate calculated using data for one sex only.

**simultaneous.** Existing or occurring at the same time. Separate *cancers* are simultaneous if diagnosed within two months of each other.

**site.** The place, position or location; for *cancer*, the *anatomic site* where the malignancy occurs. See also *primary site* and *secondary site*.

**site specific.** Pertaining to a particular primary *cancer*, e.g., surgery codes are individualized to particular cancer *sites* (breast, colon, lung, etc.).

smear. A specimen for microscopic study prepared by spreading the material across a glass slide.

squamous cell. A flat, scalelike epithelial cell.

**stage, stage of disease.** A broad category which groups cases with similar prognoses based on how far the disease has spread from the *site* of origin at the time of *diagnosis*; e.g., *in situ*, *localized*, *regional*, or *distant*; or stage 0, I, II, III, or IV.

**stem cell transplant.** A type of *bone marrow transplant* in which stem cells (the immature cells from which all blood cells develop) are obtained from the bloodstream and then used to restore the bone marrow.

stereotactic technique (s. radiosurgery or surgery). Any of the techniques which use a system of three-dimensional coordinates to precisely locate the pathologic lesion or tumor to be removed or treated. The lesion is localized using precise images, usually made by computerized axial tomography or magnetic resonance imaging. The operative approach or irradiation is then directed by an apparatus called an arc guidance system.

**subsequent treatment.** Treatment administered after failure of the *first course*, due either to progression of the disease or lack of response to the initial treatment.

**surgery.** In *cancer-directed treatment*, an operative procedure to remove cancer tissue, even if the cancer tissue is known to be not entirely removed.

**survival.** The length of time a patient lives after some defined starting point; in *cancer* data management, the length of time after *diagnosis* of cancer.

#### Т

**teratoma.** A true *neoplasm* made up of a number of different types of tissue, none of which is native to the area in which it occurs; most often found in the ovary or testis.

**text.** A term used to describe a data field that will accept any letter, number, symbol, or space; the narrative, descriptive information recorded in an abstract to justify the codes selected for the data items or to maintain information that is not coded at all.

therapy. The treatment of disease.

tissue specimen. Organs or tissue surgically removed for pathological examination and diagnosis.

**TNM Staging.** A cancer staging scheme developed by the American Joint Committee on Cancer that classifies primary *tumor*, *regional lymph nodes*, and *distant metastasis*.

topography. The name of an anatomic site or region.

transsexual. A person whose external anatomy has been changed to that of the opposite sex.

*treatment.* The management and care of a patient for the purpose of combating disease.

**tumor.** A swelling or mass; a new growth of tissue in which the multiplication of cells is uncontrolled and progressive; also called *neoplasm*. A tumor can be either *benign* or *malignant*.

*tumor board (cancer conference).* A meeting of medical professionals where the *diagnosis* and *treatment* of patients with *cancer* is discussed.

**tumor marker.** A substance in tissue or body fluids that can be measured quantitatively by biochemical or immunochemical means in order to detect a *cancer* and possibly the organ where it resides, to establish the extent of *tumor* burden before *treatment*, and to monitor the response to therapy.

tumor registrar. See cancer registrar.

tumor registry. See cancer registry.

U

## ٧

*validity.* The degree to which a measurement actually measures or detects what it is supposed to measure; accuracy.

**visceral peritoneum.** The peritoneum reflected at various places over the viscera, forming a complete covering for the stomach, spleen, liver, ascending portion of the duodenum, jejunum, ileum, transverse colon, sigmoid flexure, upper end of rectum, uterus, and ovaries. It also partially covers the descending and transverse portions of the duodenum, the cecum, ascending and descending colon, the middle part of the rectum, the posterior wall of the bladder, and the upper portion of the vagina. The peritoneum serves to hold the viscera in position.

viscus (pl. viscera). Any large interior organ in any one of the three great cavities of the body, especially in the abdomen.

# W

**Wilms tumor.** A rapidly developing *malignant* mixed *tumor* of the kidneys, made up of embryonal elements; also called nephroblastoma. It usually affects children before the fifth year, but may occur in the fetus and rarely in later life.

Χ

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Ζ